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ABSTRACT

Developed as part of Delta College's Parent Awareness Program, this manual offers parents and family members of handicapped children explanations of the following conditions: mental retardation, cerebral palsy, epilepsy, learning disabilities, and autism. In the first section, "Special Parenting Information," Gerri Caesar describes her own feelings as the parent of a handicapped child and those feelings which other parents have expressed to her as a professional. The reactions of denial, anxiety, depression, guilt, and anger, are discussed, and ways of dealing with these feelings are suggested. Next, the manual provides information on the definition, prevalence, and causes of mental retardation; and presents material on Rh blood factor, rubella, phenylketonuria, fetal alcohol syndrome, spina bifida, and Down's Syndrome. The next section offers information on cerebral palsy and other physical or neurological impairments, including material on symptoms, diagnosis, types, causes, and treatment. The section following explores various aspects of epilepsy, including seizure types and occurrences, causes, diagnosis, and treatment. Learning disabilities are examined next, with explanations of their types and causes, and the environmental, psychological, and physiological factors associated with the condition. The final section defines autism and discusses its causes, prevalence, and treatment. Each section provides a list of references. (EJV)

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* * * DEVELOPMENTAL DISABILITIES MANUAL * * *

PARENT AWARENESS PROGRAM

Program For Parents/Families of
Developmentally Disabled Children, Adolescents, and Adults

1984 - 1985
(Revised)

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DEVELOPMENTAL DISABILITIES

INTRODUCTION

The term *developmentally disabled (DD)* is commonly used by professionals and agencies servicing handicapped persons. Developmental disability has been defined by the Rehabilitation and Comprehensive Services and Developmental Disabilities Amendments of 1978 (P.L. 95-602) as follows: "A severe, chronic disability of a person which

(A) is attributable to a mental or physical impairment or combination of mental and physical impairments;

(B) is manifested before the person attains age twenty-two;

(C) is likely to continue indefinitely;

(D) results in substantial functional limitations in three or more of the following areas of major life activity; (a) self-care, (b) receptive and expressive language, (c) learning, (d) mobility, (e) self-direction, (f) capacity for independent living, and (g) economic sufficiency; and

(E) reflects the person's need for a combination and sequence of special, interdisciplinary, or generic care; treatment, or other services which are of extended or life long duration and are individually planned and coordinated."

This manual is devoted to an explanation of the following conditions: Mental Retardation, Cerebral Palsy, Epilepsy, Learning Disabilities and Autism. It should be kept in mind that these developmental disabilities may occur in isolation or in combination with one another (or with other handicapping conditions).

SPECIAL PARENTING INFORMATION

By Gerri Caesar

Parent of a Handicapped Child and
Executive Director of the Association for Retarded Citizens (ARC)
Saginaw, MI

FEELINGS

As I sit in my cottage up north, it is quiet. My husband and handicapped son are raking the yard. It is a good time for me to respond to the request made to me to write about the feelings that I have felt as a parent of a son with handicapping conditions and those feelings which parents have expressed to me as a professional. When I was first asked to write about feelings, it was interesting how I began to reflect on past events which caused me to have feelings associated with pain and joy. What really started the thinking process was the day I sat with a parent at an Individual Education and Planning Committee (IEPC) meeting. The mother suddenly burst into uncontrollable tears. Because of something said, old feelings and emotions suddenly returned. She was feeling old fears, anxiety, anger and hurts which were under the surface, ready to be awakened. This event brought to mind how parents of handicapped children are vulnerable to the feelings which produce pain.

The vulnerability perhaps began at that awful moment of disclosure when the doctor told us our child was not normal. Or it may have started when we suspected something was wrong and we began to ask questions. The initial feelings may have been disorientation. You couldn't believe this was happening to you and your family. Perhaps this was just a nightmare, someone will soon tell us it's not so. We asked ourselves many questions, perhaps afraid to say them out loud for fear we would scream or go out of our mind. "How will we manage?" "Who can help us?" "Will the pain and hurt ever go away?" "Why me?" Once I heard an extremely honest mother whisper, "I don't know if I

can love this child." I wonder how many parents ask that question of themselves but not to others, dreading what people will think of them. Perhaps there are no words or too many words to describe the feelings of shock, and despair that nothing can be done.

As we watch very young children grow and play the games that children play, we remember how we first played house. There was a father, mother, and the perfect baby. We grew older, and our dreams and fantasies of the perfect child or children continued. There were many reasons why we wanted children. Our daughters would be graceful and beautiful. Our sons would stand tall and handsome. Our children would carry on our family name. In our dreams, our children would be an expansion of our physical and psychological self. They would be all the things we had wanted for ourselves but hadn't accomplished. They would receive scholastic recognition and achieve success in their vocations. Some of us even dared to dream our children would be the president of the United States. We knew our children would be dependent on us in infancy and that dependency would continue in adulthood. They would continue to come to us for advice and guidance. There were those of us who had children because they would be personal love objects. They would love us and we would love them. And then we married and had children. We would begin our family. There would be a father, the mother and the perfect baby. After all, wouldn't our dreams come true? Then as our child is placed in our arms, we hear the words, "Your baby is handicapped" or did they say "disabled" or "mentally retarded?" Whatever terminology was used, you knew your baby was

different or not normal. Dreams and fantasies were shattered. "What about my needs, yearnings, wishes and dreams?", you asked. I remember so well the expectant father who told me that when asked if he wanted a boy or girl, he replied, "I don't care just as long as the child isn't one of those mongoloid babies." His child was Down Syndrome.

The feelings parents immediately begin to experience have been described by Pearl Buck in her book, "The Child Who Never Grew," which was to later become an analysis of the grief process. Dr. Kenneth Moses tells us, "Grief is that process whereby an individual can separate from someone or something significant that has been lost. Without the ability to grieve, a person cannot separate from a lost person or "object" and, thereby, in essence "dies" with whatever or whomever is lost." As parents of handicapped children, we are well aware of the grieving process, but we do not have the literary skills to put those feelings into words.

*Buscaglia, 1975; Sol Gordon, 1975; Kubler-Ross, 1969; Moses, 1977, 1979; Stewart, 1978; and Webster, 1976; have verbalized the feelings we have experienced. Grieving is not something you have to learn, it is what we have felt. We know all too well that the grieving process involves denial, anxiety, depression, guilt and anger. These occur in no order and often a person can feel more than one at a time. We cannot grieve alone, we need support from our spouse, relatives, friends, and professionals. I can remember very well the support I was given. Our pediatrician asked a parent of a retarded child to call me. I didn't know the mother, but she offered acceptance, friendship, compassion, and understanding. After all, she knew what I was feeling.

She had been there. Perhaps that relationship was the beginning which lead me to develop the Association for Retarded Citizens/Saginaw County Pilot Parent Program.

Dr. Moses simply describes the grief process in relationship to parenting a handicapped child as, "The Loss of the Dream of the Perfect Child." He tells us as in all grief, grieving is the catalyst of growth, and to grow, there must be successful grieving. It is a feeling or emotional process. Once that dream has been grieved, new and more attainable dreams can be generated. It is important to note the mother at the IEPC (Individual Education and Planning Committee) meeting demonstrates to us the grief process is life long and events in our child's life are likely to again trigger mourning experiences because of the loss of other dreams. Those feelings and emotions are again felt in order that we can search out other dreams which are more attainable. The awareness of this would be disturbing if we did not keep in mind that we are growing, and as parents of handicapped children, we were not given a rose garden. But for that matter, no parent was given one.

DENIAL

Parents cannot prepare for heartbreak, therefore, they are shocked when they first see signs that their child is different, slow or delayed. It is natural to avoid pain. Parents often will say their child is just slow and will grow out of it. Many times the mother becomes impatient with the husband because she has accepted, but he has not. It is wise to remember a father is often aggressive, competitive, successful and, therefore, a handicapped son is a blow to his ego.

The way parents handle this period may harm their relationship with each other and other family members. Dr. Moses tells us that through denial, we buy time. Parents need time to find inner strength, that they didn't know they had to cope with reality. Professionals, friends, and relatives should not fight parents who are going through the denial stage. It's necessary! Parents need a period of time when they obtain the needed external supports and internal strengths to deal with the full impact of the loss. It is fascinating to me as a professional to watch parents grow and observe their ability to get through this stage.

ANXIETY

Webster defines anxiety as a state of uneasiness; apprehension; and worry. Anxiety is somewhat like physical shock which enables the victim to hold on to life until help arrives. Frequently parents become preoccupied and withdrawn. They realize life will be different. Their world suddenly is falling apart. These feelings force them to react; they must change their direction. Anxiety mobilizes them. They look at the future differently. They begin to make new plans. They examine their values. Dr. Moses tells us, "The implication of this is that anxiety needs to be accepted as it is, not calmed, medicated, soothed or explain away." It is an integral part of the grieving process.

DEPRESSION

If parents are allowed to express their sorrow, they find acceptance much easier. In addition, these feelings help parents redefine their personal sense of competency, capability, value and strength. In short, it helps them to know who they are. Reaction to parents

often sounds like this: "There's no point crying over spilled milk," "Let's not talk about their handicapped child in front of them," "Let's humor them-make them smile so they forget." These ways of treating parents are all wrong. It's quite natural that parents would feel depressed about having a handicapped child. Their feelings are legitimate. Feelings of depression provoke questions such as, "What's wrong with me if I can't fix this horrible problem?" If parents are not allowed to cry and express their depression, they feel that no one cares enough to listen and agree that this is terrible. Suicide can appear attractive.

GUILT

This is the process in which parents begin to ask, "Why me?" that extends into, "What did I do to cause this terrible thing?" Dr. Moses in his teachings, tells us our meaning of life philosophy changes throughout our lifetime. He tells us this change occurs through maturity and definitely changes when confronted with the loss of a significant dream. The feeling of guilt promotes the reevaluation of one's overall life philosophy. All the feelings within the grief process are necessary, it is important for support persons to leave space for parents to deal with thier guilt. Let them talk, it will help them come up with answers for themselves. Others cannot fix it or make it go away. Simply accept their feelings.

ANGER

In guilt we asked, "Why me?" in anger we ask, "Why not you?" In anger we reevaluate our concepts of justice. Who is the real source

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of the parent's rage? Could it be the impaired child? But, of course, parents feel they "shouldn't" feel anger toward their child. As a result, the parent has a lot of trouble admitting their anger. As a consequence, most people displace their anger on the person(s) they need the most (spouse, or siblings). Professionals (doctors, therapists, teachers, etc.) are the groups that also receive the parent's displaced anger. As a parent, I have found this the hardest feeling to deal with or to understand. Facilitating grief includes the caring acceptance of the parent's anger.

Successful grief requires the sharing of these feelings of mourning with others. I have been fortunate to have grown as a result of all the feelings which I have described and the help others have given me by listening and allowing me to develop my feelings. In our family, there was a father, the mother, three perfect babies and the handicapped baby. We have indeed had the feelings which are associated with the grief process and we will go through it many times in our continuing search for attainable dreams. But we have had other feelings. We have found joy in our son who continues to help us and himself reach for new dreams and to let old dreams die. Our son has been allowed to grow and he has helped us grow. He has taken risks. He has not allowed us to shelter him. He has done things professionals have said he would never do. He has become a man, a young man who has given us feelings of pride. He has given us tears of joy as well as tears of pain. The day we were the proudest of our son was not the day he first walked or spoke or did any number of things we were told he would not do. It was the day we were told by a fellow camper that when she and her family moved into the camp ground, our son helped her set up and

then said, "Some people call me handicapped, others say I am retarded, others say I have learning problems, but I know who I am and my name is Brad Caesar and I like me and I hope you will get to know and like me too." Could we as parents ask for any better feeling?

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**This writer feels that it is extremely important to mention that the information on the theory of grieving was derived directly from presentations and materials by Dr. Kenneth Moses (Workshop - Lapeer, June 1983).

MENTAL RETARDATION

Edited by Marcia Nunn

Curriculum Development Specialist

MENTAL RETARDATION

The term "mental retardation" is a general term referring to all degrees of retarded mental development. It implies that a person is slow in developing mentally and may progress at a slower rate in school.

Definition

The American Association on Mental Deficiency (A.A.M.D.) is a national organization, founded in 1876, and was originally organized to discuss all questions relating to the cause, conditions, and statistics of retarded persons. Adopted by this organization in 1973, the following definition seems to be the one most widely used and accepted today:

"Mental Retardation refers to significant ***sub-average general*** *intellectual functioning existing concurrently with deficits in adaptive behavior and manifested during the developmental period."*

...sub-average general intellectual functioning refers to a persons performance on a standardized test of global intelligence (I. Q. test). These are tests that attempt to measure a persons vocabulary, comprehension, memory, reasoning ability, judgement and visual-motor functions. Some common I. Q. tests used in the school systems are the Weschler Intelligence Scale for Children (WISC-R) and the Stanford Binet Intelligence test. (See page 80)

...deficits in adaptive behavior refers to a persons ability to adapt to his/her environment. A deficit infers that a person may need development in social skills, communication skills, self-help skills, motor skills, etc. According to this definition a person must show both sub-average intellectual functioning and a deficit in adaptive behavior in order to be classified as "mentally retarded."

...*the developmental period* is defined as the time between birth and the eighteenth birthday.

In the education system, it is necessary, not only to determine if a child is mentally retarded, but also to determine at what level a child is functioning. The Office of Education has established a classification system that attempts to help schools to plan a program that most benefits the child. It is important for parents working with the school system to be familiar with these classification terms.

Educable Mentally Impaired (EMI)

- educability in academic subjects of the school at a minimum level;
- potential for developing social and occupational skills necessary for independent adult living;
- potential for occupational adequacies to such a degree that, as an adult, can be partially or fully self-supporting;
- growth is usually normal and retardation may not be obvious until entering school;
- I. Q. range is 50-55 to 75-79.

Trainable Mentally Impaired (TMI)

- has potential for learning self-help skills;
- can learn social adjustment in the family and in the neighborhood;
- as an adult can usually learn to live semi-independently in the community, in a group home, or supervised apartment;
- can learn vocational skills needed for a sheltered workshop setting;
- I. Q. range is 30-35 to 50-55.

Severely Mentally Impaired (SMI)

- minimal capacity for functioning in sensorimotor areas;
- can talk or learn to communicate;

- can be trained in basic health habits;
- can develop self-protection skills to a minimal useful level;
- I. Q. range is below 25-30;
- can live, as adults, at home or in a community-based residence.

Prevalence

The following information has been taken from "The Prevalence of Mental Retardation," published by the ARC National Research and Demonstration Institute.

"...the President's Panel on Mental Retardation estimated that 86.7 percent of the retarded population was mildly retarded, 10 percent was moderately retarded, and only 3.3 percent was severely or profoundly retarded."

The prevalence studies seem to agree that about 900,000 people in the United States have intellectual functioning below the 50 I. Q. range.

Some phenomenon that affect the results of prevalence studies are given below:

- a small prevalence of retardation among preschoolers;
- a gradually increasing number of mentally retarded among school-age children (reaching a peak at about age 13);
- a sharp decrease in prevalence among the population older than 16;

Some possible explanations:

- numerous cases of mental retardation among preschoolers and adults go undiagnosed;
- when mentally retarded youngsters attend school, they are likely to be discovered by teachers or school psychologists;
- after they leave school, agencies servicing people who are mentally retarded lose contact with them;
- a person can be retarded in some situations, but not in others. For example: Since schools emphasize intellectual challenges and demands, an individual may be considered retarded while in school, but may no longer be considered retarded once they leave this academic setting.

Causes

Recent advances in medical science have given us some insight into factors that are associated with mental retardation. Some of these can occur before conception (congenital or heriditary), before birth (prenatal), during birth (perinatal), or after birth (post-natal). Our current knowledge of these etiological factors can alleviate some types of mental retardation, but in other cases it only tells us that if certain conditions exist - mental retardation may result.

The A.A.M.D. has separated the medical etiology of mental retardation into the following ten categories:

(1) Infections and Intoxication.

(2) Trauma or Physical Agent.

(3) Metabolism or Nutrition.

(4) Gross Brain Disease (Post-Natal)

(5) Prenatal Influence.

(6) Chromosomal Abnormality

(7) Gestational Disorders

(8) Following Psychiatric Disorders.

(9) Environmental Influences.

(10) Other Conditions

Despite medical discoveries most persons with mental retardation remain undiagnosed.

The following are descriptions of some of the more recent discoveries that have aided in the prevention and treatment of mental retardation. The suggestions given in the Down's Syndrome section are not necessarily restricted to persons with Down's Syndrome but can be applied to other persons with mental retardation.

Rh BLOOD FACTOR

Before 1968, Rh blood disease caused death or severe birth defects in 10,000 American babies each year. That year, a vaccine - Rh immune globulin - was licensed which protects against the disease.

Despite the vaccine's availability, Rh blood disease has not disappeared. Its frequency has been reduced, but one out of five American women who needs the vaccine does not get it. This places 90,000 women needlessly at risk, and results in 7,000 infants born each year with Rh blood disease.

Rh blood disease usually can be prevented by giving the vaccine to the women with Rh negative blood within 72 hours after the birth of a baby with Rh positive blood.

Question: What is the danger to a baby if the mother is Rh negative and the father is Rh positive?

If an unborn baby inherits its father's Rh positive blood type, some of the baby's Rh positive blood cells may enter the mother's bloodstream during pregnancy, and particularly at delivery. Since these blood cells are foreign to her body, it will fight them off by producing antibodies against the Rh-bearing blood cells transmitted from the baby to her blood. In a next pregnancy, these antibodies may cross the placenta to the fetus. If it too has Rh positive blood, these antibodies can destroy some of its red blood cells. This is the danger.

In first pregnancies, the risk of damage to an Rh positive fetus is very low. Usually, the baby is born safely before the mother's body can make enough antibodies to do any harm. Rh positive babies born later, however, may be affected. Any Rh positive cells that previously entered the mother's bloodstream may have set up an antibody defense mechanism within her blood. If so, the fetus risks anemia, jaundice, brain damage, or even death.

Question: How does the Rh vaccine prevent this from happening?

The vaccine prevents Rh antibodies from forming in the mother's bloodstream. The effect lasts long enough for any of the baby's Rh positive blood cells which may have entered the mother's bloodstream to wear out and disappear. In her next pregnancy, it will be as if she were having a first baby again, as far as Rh incompatibility is concerned.

RUBELLA

About 50,000 American children died before birth or were born with defects because their mothers contracted rubella while pregnant during the 1964-65 epidemic. The vaccine, which was licensed in 1969, ultimately can eliminate rubella.

Many people know it only as three-day measles--an innocent-sounding alias.

About one in seven women of childbearing age in this country are still susceptible to rubella. This lack of immunity endangers the fetus if a women catches rubella during pregnancy. The first three months of pregnancy are the time of greatest risk to the baby.

Women of childbearing age should receive vaccine only if they are not pregnant and understand that they should not become pregnant for three months after vaccination.

A doctor can tell from blood tests taken before and at intervals during pregnancy whether a women is susceptible to rubella.

Rubella symptoms, ironically enough, are quite mild: low-grade fever, a rash starting on the face and spreading down the body, and swelling of the lymph glands in the neck. These signs may be so slight that a pregnant woman doesn't even know she's had the disease--until her child is born with defects. Rubella is a well-known cause of mental retardation.

(Information for "Rh Blood Factor" and Rubella" was provided by the March of Dimes - Birth Defects Foundation)

PHENYLKETONURIA (PKU)

PHENYLKETONURIA (PKU) is a rare inherited disease which usually causes mental retardation unless it is detected and treated very early

in life. In addition to mental as well as physical retardation, symptoms such as restlessness, irritability, skin rashes, and seizures may be present in the untreated PKU child.

Today, the mental retardation associated with PKU can be prevented because of the availability of an effective screening program and a special diet.

PKU is passed on to a child when both parents carry the gene which produces the PKU condition. (Genes are in all the cells of the body, and determine characteristics such as eye color and hair color.) When both parents are PKU "carriers," and as such are not affected by the disease themselves, there is a one-out-of-four chance that they will have a PKU baby, but a three-out-of-four chance in each pregnancy that they will not have a child with PKU.

A baby with PKU is born with genes which are unable to produce a specific enzyme (phenylalanine hydroxylase). This enzyme ordinarily "changes" or metabolizes a substance called phenylalanine. Because of the absence of this enzyme in the PKU child, the phenylalanine cannot be metabolized and thus is accumulated in the child's body. While phenylalanine is an important building block of protein needed for growth, this abnormal increase of phenylalanine and its by-products can damage the developing baby's brain and thus lead to mental retardation.

The presence of PKU disease in a newborn is discovered when a few drops of blood from the baby's heel are taken in the hospital nursery, absorbed on filter paper, and mailed for a screening test to a reliable laboratory. Should these further tests confirm that the baby has PKU disease, he is given a low phenylalanine diet since cow's milk and many baby formulas, as well as milk products and meat, are high in phenylalanine.

(Information taken from: PKU and Your Newborn Child., Massachusetts Association for Retarded Citizens, (pamphlet).

FETAL ALCOHOL SYNDROME

Symptoms

Full Fetal Alcohol Syndrome (FAS) includes:

- small size (length and weight)
- abnormally small head
- mental retardation, I.Q.'s as low as 16, but as high as 112 (a normal I.Q. is considered to be 100)
- peculiar face which can include--
  - flattish appearance in profile
  - narrow, slit-like eyes with drooping lids and/or squint
  - flat cheeks
  - short, upturned nose (area between nose and upper lip is elongated; vertical groove is flattened or missing)
  - narrow upper lip (gives mouth a fish-like shape)
  - blunt jaw, receding chin
  - deformed ears set low on head
  - characteristic brain malformations

FAS may also include other deformities--

- heart murmurs
- joined or bent fingers, toes, or elbows; extra finger or toe; fragile fingernails
- abnormally deep crease on palm running down between second and third fingers
- hip dislocation, stiff joints, other bone damage
- kidney/genital problems
- hernias, other muscular problems
- benign tumors
- cleft palate

Seen in older children;

- mental retardation (this is irreversible)
- hyperactivity, with retarded mental processes
- difficulty in sustaining activity
- behavior problems in school
- skinny appearance (their parents and foster parents claim they cannot "fatten up these kids" no matter how much they eat)

(Information taken from: "Just So It's Healthy," by Lucy Barry Robe)

SPINA BIFIDA

Spina bifida is a birth defect of the backbone (spinal column), often called "open spine." Some 1,500 babies (one in 2,000) are born with this condition each year in the United States. It is more frequent in Ireland and Wales, and less common in Israel and among Jewish people in general.

Question: How does spina bifida affect a child?

Every unborn infant's spine is open when it first forms, but normally it closes early in a mother's pregnancy. In spina bifida, the backbone never closes completely. There are three forms of spina bifida:

The defect may be so slight it never bothers the child and is only discovered accidentally, through an X-ray taken later for some other condition.

A cyst, or lump, containing part of the spinal cord pokes through the open part of the spine. The lump under the skin can be as small as a nut or as large as a grapefruit, and if it is in the lower back it may cause weakness in the legs. This lump can be removed by surgery, allowing the baby to grow normally.

In the most severe form of spina bifida, the cyst holds deeper nerve roots of the spinal cord. This lump has little or no skin protecting it. Spinal fluid may leak out, and the area often is covered with sores. Infection is a danger until surgery and healing takes place. Since this severe type is usually at the lower end of the spine, the baby's legs are paralyzed and have no feeling. Poor bladder and bowel control later become a problem.

Hydrocephalus

Hydrocephalus (water on the brain) occurs in 70 to 90 percent of children with severe open spine. This happens when spinal fluid collects in and around the brain, causing the head to become enlarged. If the fluid isn't drained away regularly, mental retardation may result. Hydrocephalus may also occur without spina bifida.

Treatment

When the spinal defect is so slight that it is hardly noticed, no treatment is needed. If there is a lump but no leg paralysis or loss of feeling, doctors can operate to prevent damage.

When a baby is born with the most severe form of spina bifida, it usually is operated on at once--within 48 hours after birth. Doctors remove the large, runny cyst and cover the wound with muscle and skin, Even so, the leg paralysis and lack of feeling cannot be cured.

As soon after the operation as possible, a physical therapist teaches the parents how to exercise their baby's legs and feet to prepare it for walking with leg braces and crutches. Some children may need to use a wheel chair.

If the child develops hydrocephalus, fluid can be drained from its brain through a special tube. The tube runs under the skin down into the chest, and the fluid passes harmlessly through the child's body.

(Information taken from: March of Dimes, Public Health Education Information Sheet)

DOWN'S SYNDROME (MONGOLISM)

Terminology

The term "Down's Syndrome" refers to a diagnosis of mental retardation that is characterized by specific features of persons with this syndrome.

An English physician, J. Langdow Down, first proposed the classification and description (Mongolism) based on characteristics of that ethnic group (the Mongolian race) in 1866. Partly because the term "Mongolism" suggested a racial or physical relation to an Oriental people, and partly because of past misconceptions about persons with this syndrome, the classification was changed to "Down's Syndrome."

Cause

In the 1950's a series of major medical advances improved techniques for examining the human chromosomes (the carriers of genetic material critical to growth and development). Jerome Lejeune (1959) discovered that a child with Down's Syndrome has one extra small chromosome in every body cell.

This extra chromosome is responsible for producing the alterations in physical and mental development.

A normal child receives 46 chromosomes (23 from mother - 23 from father). When fertilization of an egg occurs, the 46 chromosomes unite to form 23 matching pairs in each normal cell. A person with Down's Syndrome usually has 47 chromosomes (three #21 chromosomes instead of the usual two). This type of Down's Syndrome is referred to as Trisomy 21.

Normal Cell	Down's Cell (Trisomy 21)
46 chromosomes	47 chromosomes
23 matching pairs	3 chromosomes in the #21 pair

When a mistake in chromosome distribution results in some cells being normal, and some cells having the trisomy 21 (three chromosomes in the #21 chromosome), the admixture is called 21 trisomy/normal mosaicism. Because a person with this type of Down's Syndrome has a normal chromosome complement in some cells, he/she may have fewer of the physical characteristics and higher mental performances than a person with 21 trisomy in all cells.

When the extra #21 chromosome has broken and its long arm is attached to the broken end of another chromosome, the syndrome is referred to as translocation.

In about one-third of translocation 21 trisomy cases, one of the parents can be a genetically balanced carrier of the translocation chromosome. The parent does not have the third #21 chromosome, but one of his/her two #21 chromosomes is attached to another chromosome (a total of 45 chromosomes, instead of the normal 46). This will not alter the balance and function of the parents genes, but may cause chromosome distribution problems when an egg or sperm are joined from the other parent.

If the mother is the carrier, the risk of having a Down's Syndrome child is approximately 10 percent with each pregnancy. If the father is the carrier, the risk is about 2 percent (the sperm carrying the chromosome imbalance is less likely to be the first one to arrive to fertilize the egg - this selection does not exist for the egg). If chromosome studies are done, it is important to examine the chromosome of both parents to ensure that neither is a balanced carrier of the translocation.

Regardless of the type of Down's Syndrome, the #21 chromosome is responsible for the physical features and the mental deficiency observed

in a person with Down's Syndrome. However, it is yet unknown in what way the extra chromosome interferes with higher development.

General Risk and Recurrence Risk for Down's Syndrome

The faults in chromosome distribution are not rare. At least 4 percent of pregnancies begin with an unbalanced chromosome set in the beginning cell. Most genetic imbalances do not allow for the continued development of the growing embryo.

The occurance of Down Syndrome is closely associated with the age of the mother. After age 30, the the likelihood of Down's Syndrome approximately doubles for each successive five-year period.

Under 30 years	30-34 years	35-39 years	40-44 years	45 plus years
1 in 1,500	1 in 750	1 in 280	1 in 130	1 in 65

Prebirth Detection of Down's Syndrome

Parents have a relatively high risk of having a child with Down's Syndrome if:

- the pregnant woman is a balanced 21 chromosome translocation carrier
- the father is a balanced 21 chromosome translocation carrier
- the couple has had more than one child with 21 trisomy Down's Syndrome
- the mother is in older age group (especially over 40 years)
- the mother has had one full 21 trisomy Down's Syndrome child

A majority (approximately 92 percent) of persons with Down's Syndrome have a full Trisomy 21 (three #21 chromsomes present in every cell), 3-4 percent of persons with Down's Syndrome have 21 Trisomy/normal mosaicism (some cells are normal and some are 21 trisomy) and 1-2 percent of persons with Down's Syndrome have translocation 21 trisomy (the extra #21 chromosome has broken and attached to another chromosome). About 6 percent of these (translocation 21 trisomy) are born to young parents.

It is recommended that mothers over thirty-five undergo a procedure called amniocentesis. Through this procedure fluid is obtained from the mother's womb (between the 14th and 16th week) and the fetal cells examined. Amniocentesis is also recommended for mothers who are translocation carriers (any age) and mothers who already have a child with Down's Syndrome.

Characteristics (a child with Down's Syndrome will not necessarily have all the characteristics)

Physical Features - used primarily to aid in making a diganosis

Muscle tone: tend to have less but improves with age.

Head: the back of the head may appear less prominent and a bit smaller than average.

Nose: tends to be small and the bridge somewhat low - face may appear relatively flat.

Eyes: tend to slant upward. There may be small folds of skin at the inside corner.

Ears: usually small, and sometimes prominent; top rim of the ear is frequently folded over slightly.

Mouth: tongue is normal size, but the mouth may be relatively small and the roof of the mouth a bit short.

Teeth: may be a bit small and are sometimes abnormally placed in unusual positions or sometimes one or more are missing.

Voice: slightly deep quality in early to late childhood; speech is usually late and talking clearly may be difficult.

Neck: frequently appears short.

Heart: about 40 percent have a defect in the development of the heart.

Hands: appear small, with relatively short fingers; fifth finger may be shorter and tip of this finger frequently turns inward.

Feet: small gap between first and second toes.

Skin: may have a mottled appearance and could become dry as a child grows older. (may chap easily)

Hair: tends to be sparse, fine, and straight.

Linear Growth: are usually shorter than average and appear stocky in build; growth rate is just slightly behind average until age 4; around 4 years the rate of growth begins to fall below the normal ranges with each successive year. Average height for men is about 5 feet; average height for women is about 4 feet 7 inches.

Weight Growth: tend to be within normal ranges at birth; as they grow older, tend to correspond with their shorter height; mild to moderate obesity is not uncommon in late childhood and adulthood; parents may want to supervise eating habits.

General Health in Childhood: if a child with Down's Syndrome does not have any of the more serious physical problems, it is most likely that he will be healthy and not present many difficulties in general care; he will be susceptible to the usual childhood illnesses and may be more prone to ear, eye, or respiratory tract infections; he will require normal dental care (tend to have fewer cavities than other children); toilet training, bathing and personal hygiene usually require supervision to a later age than usual.

Adolescent and Sexual Development: sexual development may be late, uncomplete, or both; males tend to produce less male hormone and may have a small penis and less facial hair than usual; females may have only mild to moderate breast development, but menstruation usually begins at the usual age.

It should be noted here that although the presence of the extra #21 chromosome may cause a number of physical characteristics which makes him look somewhat different from others, the person with Down's Syndrome inherits genes from both his mother and father and will most likely have similar body build, hair and eye color, and follow growth patterns observed within his family.

Mental and Social

The trisomy 21 that effects the physical make-up of a person with Down's Syndrome, also effects the development and function of the brain. The brain in turn, controls muscle coordination, the five senses, intelligence, and many aspects of behavior. Although a person with Down's Syndrome is more limited and may respond at a slower pace, it is important that he be encouraged to develop all of his abilities. He needs stimulation to

ensure a sense of accomplishment, especially in early years when development is proceeding at its greatest pace. Every person with Down's Syndrome is different; many teen-agers and young adults can live together under supervision in the community, maintaining limited jobs and partially supporting themselves.

The following suggestions and concerns were taken from "Down Syndrome: Growing and Learning."

Early Developmental Stimulation

Tactile Stimulation

1) Place an infant on surfaces of varying texture, rough as well as smooth blankets, and on different kinds of floor coverings or upholstered furniture. The infant's skin should be exposed to these various tactile stimuli.

2) Cover your infant's body with materials of different textures and weights, also both cool and warm garments. Since the infant's level of activity may change under different conditions, you may want to loosen his garments to allow for freer activity or use more restricting garments to elicit stronger movements against resistance.

3) Touch your child in a variety of ways including stroking his skin, rubbing, tapping, gentle tickling and light squeezing.

4) Let the infant touch you. Place your baby's hands on your face, hair, and clothes and on various parts of his own body. Encourage touching by placing his hands on the bottle or breast during feeding. Let the baby feel different shapes and textures of toys.

5) Move the infant's arms and legs. They can be moved in simultaneous or alternate patterns. Children usually respond more actively when movements are accompanied by singing or playing rhythmic tunes.

6) When bathing an infant in tubs or sinks, do not restrict his movements. Encourage splashing and other body movements while in the water. A pleasant and easy way to bring this about is to take your baby along when you take a bath.

Visual Stimulation

A visual stimulation program provides some basic skills in looking, focusing, and exploring, following an object through a wider range, and

differentiation between objects. These skills are needed for later stages of active, purposeful grasping and reaching.

- infants like best to look at human faces (8 - 12 inches). If accompanied by sound, the interest seems to be accentuated.
- to evoke child's attention and interest;
  1) attach colorful objects above, as well as on the side, of his crib (mobiles, shiny spoons, colorful clothespins, fluttering multi-color tissue paper, balls attached to a string).
- new sensations or impressions provide your child with a better learning instrument than do familiar ones.
- place child outdoors (whenever possible) to provide varied experiences such as looking, feeling, and listening.

Auditory Stimulation

The human voice attracts and holds the infant's attention better than any other stimulus.

Suggestions for a wider variety of sound stimulation:

1) Alternating between low and high pitched voice, whispering, whistling, hissing, and blowing.
2) Use of words with a variety of vowels and consonants that produce expressive movements of the face since infants watch facial movements quite attentively;
3) Frequent smiling, laughing, giggling since the infant reacts quite differently to each of these expressions;
4) Use of sounds and words produced with varying speed, rhythm, and sounds which come from different directions;
5) Singing with varying modulation of voice.

Frequently for children with Down's Syndrome, a combination of strong visual, auditory, and tactile stimulation has to be used to elicit adequate responses. Cuddling, clapping of hands, tapping the skin, gentle tickling or stroking, as well as moving the arms and legs, are some of the ways which have been used to combine tactile stimulation such as talking, singing, playing recorded music, and attaching bells to wrists or ankles.

The most important aspect of any stimulation program is to respond positively to those reactions which show that the infant has engaged in some activity resulting in a new learning experience. Even unimpressive and slow progress may ultimately add up to a point where they may make a difference in the capacity to cope better with the number of tasks which most children with Down's Syndrome are able to learn.

Special Concerns in Adolescence

It is important that children with Down's Syndrome be encouraged to develop all their abilities, to learn and achieve as much as their potential will allow.

The transition for the adolescent attempting to move from childhood into assuming the responsibility of adulthood may be a troublesome time for those of normal intellectual abilities. For the retarded adolescent, the problems are frequently intensified. Although the retarded adolescent may have the physical attributes of normal youngsters, they often do not possess the capabilities to cope with the demands of their environment and/or their own desires for independence.

The opportunities to experience risks, to make decisions, and to assume responsibility are essential to the development of internal control, self-confidence, and independence. For the adolescent with Down's Syndrome, these experiences may, at times, be structured. However, in order to achieve independence, it is important to have many opportunities for him to make decisions, initiate actions and assume some of the responsibilities of those actions.

The adolescent with Down's Syndrome has fewer opportunities for experiences and relationships with peers and, therefore, receives less feedback and help in his struggle for independence. When children grow into adolescence, they need to understand the physical and social changes that take place during this particular period of time. The amount of information and how it is given to an adolescent with Down's Syndrome may differ from that of a non-handicapped peer. Repetition and the use of direct and simple words are necessary. It is more difficult for a retarded person to guess, to fill in, or to interpret from analysis. Information should be given in a very concrete fashion with the use of pictures, verbal explanations and specific examples.

To initiate and reinforce an attitude that is wholesome and healthy regarding their bodies and bodily functions, the adolescent with Down's Syndrome needs to learn that their responses to physiological changes that are occurring are natural and that they need to express them in socially acceptable ways.

Human Dignity

Adults with Down's Syndrome are people in their own right, in spite of their limited capacity for academic achievement. They have needs, wishes, and hopes that should be recognized. We need to offer them a status that observes their rights and privileges as citizens in a democratic society through guidance and assistance in developing their own identities and leading their lives to its fullest.

A young adult with Down's Syndrome needs to move gradually from the sheltered environment of home into the world of work and toward forming relationships with non-retarded adults.

To insure a successful program for the young adult with Down's Syndrome, cooperation between the public school, the vocational rehabilitation agency, and the sheltered workshop is essential. We need, also, to keep in mind that the purpose of work experience is not necessarily to develop specific vocational skills, but rather to enable a student to attain good work habits and interpersonal skills necessary to maintain a job.

An adult with Down's Syndrome who has finished school and job training may leave home to form new living arrangements. To meet the varied needs of the adult with Down's Syndrome out in the community, a program including vocational preparation, job placement and productive activity in a sheltered workshop or supervised employment should be developed. Also, recreational and leisure time activities will help to make life more meaningful.

DEVELOPMENTAL CHARTS

The following two pages are comparison charts depicting age ranges for development and self-help skills. These are approximate times that a child with Down's Syndrome may learn or be taught various skills. They are to be used as a guideline only, as many skills may overlap or be delayed.

DEVELOPMENTAL MILESTONES

	DOWN SYNDROME CHILDREN		"NORMAL" CHILDREN	
	average	range	average	range
Smiling	2 months	1½ to 4 months	1 month	½ to 3 months
Rolling over	8 months	4 to 22 months	5 months	2 to 10 months
Sitting Alone	10 months	6 to 28 months	7 months	5 to 9 months
Crawling	12 months	7 to 21 months	8 months	6 to 11 months
Creeping	15 months	9 to 27 months	10 months	7 to 13 months
Standing	20 months	11 to 42 months	11 months	8 to 16 months
Walking	24 months	12 to 65 months	13 months	8 to 18 months
Talking, Words	16 months	9 to 31 months	10 months	6 to 14 months
Talking, Sentences	28 months	18 to 96 months	21 months	14 to 32 months

SELF HELP SKILLS

	DOWN SYNDROME CHILDREN		"NORMAL" CHILDREN	
	average	range	average	range
Eating				
Finger Feeding	12 months	8 to 28 months	8 months	6 to 16 months
Using Spoon/Fork	20 months	12 to 40 months	13 months	8 to 20 months
Toilet Training				
Bladder	48 months	20 to 95 months	32 months	18 to 60 months
Bowel	42 months	28 to 90 months	29 months	16 to 48 months
Dressing				
Undressing	40 months	29 to 72 months	32 months	22 to 42 months
Putting Clothes On	58 months	38 to 98 months	47 months	34 to 58 months

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CEREBRAL PALSY AND OTHER PHYSICAL OR NEUROLOGICAL IMPAIRMENTS

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CEREBRAL PALSY

Description

Cerebral Palsy is a large group of movement disorders that vary from mild symptoms (child may be a little awkward) to severe symptoms (child may be extremely physically impaired). "For a disorder to be classified as cerebral palsy, not only must there be a problem with movement or posture, but the problem must also occur early in development, during the time of the brain's most rapid growth. (By age 5 the brain will have reached 90 percent of its adult weight.)

In many cases of cerebral palsy, the movement disorder may be accompanied by mental or emotional impairment, convulsive seizures (epilepsy), or impaired hearing, vision, or the other senses. Some of these associated conditions can be treated successfully, and some kinds of movement disturbance may improve in time. However, nerve cells are extremely limited in their powers of repair and regeneration, and even in cases where a child appears to recover full control over the limbs, mental or emotional deficits may remain.

On the other hand, the brain damage doesn't get worse over time: cerebral palsy is a nonprogressive disorder (although symptoms may change as a child matures). Cerebral palsy is not contagious and only very rarely are the symptoms associated with a hereditary disorder." (National Institutes of Health - Cerebral Palsy)

Cerebral palsy is not curable, however, its effects can often be diminished through training and therapy.

Diagnosis

"Generally the diagnosis of cerebral palsy is made on the basis of symptoms that develop over the first or second year of life. Cerebral palsy is frequently not evident at birth because newborns have very little voluntary control over their bodies. They depend on reflexes--automatic responses built into the nervous system. Reflexes serve to protect and preserve the baby. As development unfolds, a normal infant gradually loses the more primitive reflexes (which often involve movement of major parts of the body) and gains increasingly fine control over the body's separate parts.

In contrast, an infant with cerebral palsy usually shows a delay in development. Often the primitive reflexes remain and may dominate behavior so that the child has difficulty mastering such familiar landmarks of growth as rolling over, sitting, crawling, smiling, or making speech sounds. Sometimes an infant will favor a particular side of the body or assume an unusual posture. In other instances the major symptom may be an overall muscle weakness or decreased muscle tone (hypotonia): the baby is as floppy as a Raggedy Ann doll and even some of the primitive reflexes may be weak or absent."
(National Institutes of Health: "Cerebral Palsy: Hope Through Research")

Types

Spastic Cerebral Palsy

- the most common type of cerebral palsy;
- muscles are tense and contracted, resistent to movement;
- movements of the legs may be stiff and resemble the crossed blades of a pair of scissors (scissors gait);
- surgery can sometimes release tight hip muscles and/or heal tendons.

Athetoid Cerebral Palsy

- involuntary writhing movements of affected body parts;
- hands may turn and twist;
- sometimes there may be facial grimacing, tonguing and drooling;
- may be abrupt flailing or jerky motions of the body (chorea).

Ataxic Cerebral Palsy

- lack of balance and coordination;
- may sway when walking or may walk with feet spread apart to avoid falling;
- motor centers involved lie in the cerebellum.

Mixed Cases

- several motor centers of the brain are affected.

Other Symptoms

- hand tremors which cause difficulty in fine motor tasks;
- may be problems in speaking, chewing, or swallowing, maintaining visual focus, or following a moving target;
- jerky movements of the body;
- speech is often involved because of the difficulty in controlling muscles;
- appearance of athotosis is usually seen after 18 months of age because of its dependence on maturity of the brain and development of major motor patterns;
- fine motor movements are affected;
- child may exhibit symptons or characteristics of more than one type of cerebral palsy.

"There are hundreds of possible problems that may result in damage to the brain which in turn may be classified as cerebral palsy.

The fact that there is brain damage affecting motor control distinguishes cerebral palsy from what is typically considered to be mental retardation. Certainly, whatever the cause of cerebral palsy may be in a specific child, there remains a concern that retardation may also be present. Multiply handicapped persons may be epileptic, deaf, blind, and cerebral palsied and still not be shown to be retarded. It all depends upon the location of the damage to the brain.

Parents should recognize that there are similarities in causes of cerebral palsy and mental retardation, but one does not necessarily accompany the other." (Coping With Cerebral Palsy: Answers to Questions Parents Often Ask, Jay Schleichkorn)

Causes

The following causes of cerebral palsy are grouped into three major categories according to the period in which the potential problem may develop.

"*Prenatal*: From the time of conception to the time of labor, any one of the following may occur.

Anoxia: due to some problem with the umbilical cord;

Maternal infection: due to a viral or infectious agent such as rebella, toxoplasmosis, herpes simplex;

Metabolic disease: diabetes, heart condition, hyperthyroidism, severe asthma;

Rh factor: Rh sensitization.

Natal: From the onset of labor to the actual birth of the baby, any one of the following may occur.

Anoxia: due to some obstruction involving the cord;

Asphyxia: resulting from a mechanical respiratory obstruction;

Analgesics: administering of drugs affecting the respiratory center of the infant;

Trauma: any injury to the baby's head during labor, hemorrhage, forceps application, poor position of the infant;

Pressure changes: too fast a delivery, too slow a delivery, Caesarean section;

Prematurity: complications at birth, respiratory distress, "small-for-date" babies.

Postnatal: From the time of and after the birth of the child, any one of the following may occur.

Trauma: damage to the head by fracture or wounds;

Infections: childhood fever, meningitis, encephalitis, brain abcess;

Vascular problems: hemmorrhage, thrombosis;

Anoxia: strangulation, carbon monoxide poisoning;

Neoplasms: tumors, cysts, hydrocephalus." (Coping With Cerebral Palsy)

Other Contributing Factors

- 39 percent of children with cerebral palsy have a history of low birth weight (Scherzer and Mike, 1974). This prematurity factor refers to both the weight of the baby and the length of gestation (born before completion of the 37th week of gestation);

- Breech delivery increases the likelihood of damage to the brain due to anoxia (lack of oxygen).

Doctors sometimes classify a person with cerebral palsy according to the quality of the movement disturbances and the limbs affected. The following terms are used to describe the involved area:

Hemiplegia - involves both the arm and leg on one side of the body;

Quadriplegia - involves both arms and legs, usually a severe injury to the vertebrae damaging the spinal cord;

Diplegia - involvement primarily with the lower extremities (legs).

Treatment

Physical Therapy. A program of exercises and activities, supervised by a professional therapist, is designed to make the most of the individual's potential and to recruit whatever reserves the nervous system may have for learning new skills.

Some physical therapy programs popular today follow specific principles of nervous system development. The Bobath technique, for example, pioneered by a husband-wife team in England, is based on the idea that the primitive reflexes exhibited by many children with cerebral palsy are major impediments to learning voluntary control. The reflexes also give rise to abnormal sensations: the child's muscles always feel very tense or very loose. The therapist tries to break down the reflexes by deliberately positioning the child in opposing postures, if an arm had been extended it is now flexed, and so on. Gradually some children are able to maintain the new "reflex inhibiting postures" and begin to experience more normal muscle tone.

Other innovations to physical therapy make use of the psychological principles of behavior modification in which the individual is rewarded ("positively reinforced") for certain behavior.

Many therapists stress the importance of providing a varied and stimulating environment for the physically handicapped child. Children normally learn by active exploration of their world.

Biofeedback. One of the latest methods of treatment of cerebral palsy combines behavior modification with the techniques of biofeedback. In biofeedback an individual is supplied with information--usually in the form of vivid visual or auditory signals--about the functioning of a particular part of the body.

Now investigators have been able to train some youngsters with cerebral palsy to lower the tension of their muscles by lowering the pitch of muscle "sounds." The sounds correspond to the electrical activity generated whenever muscles contract; the greater the tension, the higher the voltage (and the musical pitch).

Occupational therapy. Occupational therapy teaches the practical skills that enable a person to say, "I can do it myself." For handicapped children occupational therapy means learning how to dress, comb hair, clean teeth, hold a cup or a pen or pencil. For older people occupational therapy may mean vocational training or learning how to shop, cook, or keep house."("Cerebral Palsy: Hope Through Research")

Prevalance

Approximately 700,000 children and adults in the U.S. have cerebral palsy (United Cerebral Palsy Association, Inc.). This amounts to about 16 out of every 5,000 people. In Michigan, that involves about 31,000 residents.

The following are some general suggestions for parents or those working closely with a person with cerebral palsy. (Taken from: Handling the Young Cerebral Palsied Child At Home, 1974)

1. "...handle a cerebral palsied child slowly, and give him a chance to make his own adjustment as you move him, supporting him where and when necessary, but waiting and giving him time to do whatever he possibly can by himself.

2. It is most important, when anything is being done for the child, that he should not be passive, let him see what is being done and talk to him about it.

3. A cerebral palsied child takes far longer than a *normal* child to understand and store information, therefore constant repetition is of real value, it should always be borne in mind that he does not have the same opportunity as a *normal* child of learning by trial and error and by experimenting.

4. Try at all times to enlist the child's cooperation. Within reasonable limits ask him what he would like to wear, what and how much he would like to eat.

5. ...whenever possible, let your child dress, wash and eat with the other children in the family, in this way he will be much more inclined to try to help himself.

6. Avoid *excessive* effort, as failure can lead to tenseness and frustration with the probable result that the child will give up. By using correct help and guidance he will learn to do more and more for himself."

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EPILEPSY

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EPILEPSY

"Epilepsy is a common neurological condition. It is sometimes called a seizure disorder. It takes the form of brief, temporary changes in the normal functioning of the brain's electrical system.

These brief malfunctions mean that more than the usual amount of electrical energy passes between cells. This sudden overload may stay in just one small area of the brain, or it may swamp the whole system."

SEIZURE TYPES

"Epileptic seizures may be convulsive or non-convulsive in nature, depending on where in the brain the malfunction takes place and on how much of the total brain area is involved." ("Epilepsy: Recognition and First Aid" Epilepsy Foundation of America, 1983)

Generalized Convulsive (the most common and most noticeable type of major seizure).

- Sometimes called "tonic clonic" or "grand mal"
- Nerve cells discharge throughout the brain
- May occur at any age
- May last one to several minutes
- May occur once a day or once every few years
- Most likely to respond to treatment

Symptoms

- Loss of consciousness
- Stiffening and shaking of entire body
- Violent jerking of limbs
- Rigidity, irregular breathing

A seizure of this type usually starts with a hoarse cry caused by air being suddenly forced out of the lungs. The person falls to the ground (unconscious), his body stiffens briefly, and then begins jerking movements. Sometimes there is a loss of bladder or bowel control and the tongue may be bitten. A frothy saliva may appear around the mouth because of the air being forced through mouth fluids. Breathing may become very shallow or stop for a few moments. The decreased rate of breathing (supplying less oxygen) may cause the skin to turn a bluish color. When the jerky movements slow down and the seizure ends (after a few minutes), the person will return to consciousness and may feel confused and sleepy.

Non-convulsive

1. Absence or Petit Mal
   - Short periods of staring or blanking out spells
   - Last only a few seconds
   - Affects awareness
   - Nerve cells discharge throughout the brain
   - Most common in children age 6 - 14
   - May occur dozens or even hundreds of times a day

A child having this kind of seizure is momentarily completely unaware of people and things around him, but quickly returns to full consciousness without falling or loss of muscle control. Some children may stumble and fall if having this type of seizure while playing or running around. The seizures happen very quickly and may go unnoticed. Often times, a parent or teacher thinks the child is being unattentive or is daydreaming. These seizures may also produce blinking or chewing movements, turning of the head, or waving of the arms.

2. Simple Partial (unusual movements)

   - Sometimes called Jacksonian
   - Person knows what is going on during the seizure but cannot control his movements.
   - Movements involve trembling or jerking of an arm or leg
   - Movements sometimes start in a finger and "march" upwards until the whole hand and arm are shaking

3. Simple Partial (unusual feelings)

   - Sometimes called "sensory"
   - Things may look strange or may see things that aren't there
   - May hear strange sounds
   - May have a feeling that what is happening around him is somehow happened before

The seizure activity is taking place in parts of the brain that control seeing, hearing or memory.

4. Complex Partial

   - Sometimes called "psychomotor" or "temporal lobe"
   - Nerve cells discharge in one part of the brain
   - May occur at any age but is most common in teenagers and adults
   - Person looks as if he is in a trance
   - Goes through a series of movements over which he has no control
   - There is usually a pattern of behavior (referred to as automatic behavior) that each person follows every time a seizure occurs

A typical seizure will start with a strange sensation (feeling of fear, sudden sick feeling in stomach, seeing or hearing something that isn't really there), followed by staring blankly or making chewing movements with his mouth. He may move an arm, pull at clothing, get up and walk around. Although not aware of things and people around him, he may follow simple directions if given calmly. The seizures last for only a

minute or two, but full awareness may not return for some time afterwards. This may be followed by confusion, irritability and he may not remember what happened during the seizure.

5. Atonic Seizures
   - Also called "Drop Attacks"
   - Affects children between 2 - 5 years of age
   - Symptoms include clumsiness and lack of good walking skills
   - Last for 10 seconds to 1 minute
   - The child should have thorough medical evaluation
6. Myoclonic Seizures
   - Characterized by sudden, uncontrolled jerks of part of a limb, the whole limb, or the whole body
   - Usually occurs during the early part of the day
   - Person usually loses consciousness momentarily and may be confused
   - Person should have a complete medical evaluation
7. Infantile Spasms
   - Starts between 3 months and two years
   - Characterized when lying down by; the legs being drawn and arms and head flexing forward as if the baby is reaching for support
   - Baby should have a prompt and thorough medical evaluation

CAUSES

In about half of all cases (1 percent of the population) of epilepsy there is no one cause that can be found. Although scientists know how seizures occur, they don't know why. Among the remaining other half of people with epilepsy, the cause may be attributed to a number of things

that make a difference in the way the brain functions. These related factors are as follows: head injuries, lack of oxygen during birth, brain tumors, genetic conditions (errors in metabolism), alcohol or lead poisoning, problems in development of the brain before birth, and illnesses (meningitis, encephalitis, or measles).

FIRST AID (Generalized Convulsive)

Do's	Don'ts
- Protect from nearby hazards - Loosen ties or shirt collars - Place folded jacket under head - Turn on side to keep airways clear - Reassure when consciousness returns - If multiple seizures, or if one seizure lasts longer than 10 minutes, take to emergency room	- Don't put any hard implement in the mouth. - Don't try to hold tongue. It can't be swallowed. - Don't try to give liquids during or just after seizure. - Don't use oxygen unless there are symptoms of heart attack. - Don't use artificial respiration unless breathing is absent after muscle jerks subside, or unless water has been inhaled. - Don't restrain.

SEIZURES

Recent research indicates that some children with early diagnosis and treatment have a good chance of eventually living without medication or seizures. However, many people who receive optimal medical treatment may continue to have seizures occasionally.

The regularity of seizures is important in determining a persons limitations. Some seizures are entirely confined to sleeping hours or on first awakening (these do not limit daily functioning). Some women have a clustering of seizures around the time of menses (these can be predicted). Some seizures start in response to flickering lights, watching television, or not getting enough sleep (these people can avoid the circumstances). Some people receive a warning that is distinct from the

aura (a part of the seizure itself). These may occur minutes or hours before a seizure (headaches, abdominal discomfort, and feelings of euphoria or depression).

Aura

> "The beginning of a seizure as recognized by the patient; a sensation immediately preceding an epileptic attack, may be noises in the ears, flashes of light, vertigo, etc."
>
> (Taken from the Glossary of Plan For Nationwide Action On Epilepsy, Publication No. 78-276 of the National Institutes of Health.)

DIAGNOSIS

Parents provide doctors with the single most important clue to an accurate diagnosis of epilepsy - a neurological history of their child.

A neurologist is a doctor who specializes in epilepsy (and other conditions involving the brain). He needs, in addition to a complete history, a neurological examination and laboratory tests to confirm a diagnosis and to help him determine, not only the kind of medication, but also the amount. Parents can provide him with vital information about the events surrounding a seizure and behaviors associated with the seizure.

TREATMENT

Medication - Drugs

The neurologist uses his acquired knowledge to help him make a decision about the treatment required. Some drugs work on several different types of seizures and some are suited to specific types of epilepsy. For most types of seizures, a regular use of one or more chemical substances (drugs) are prescribed.

These medications (called anticonvulsants) tend to limit the spread of seizure discharges within the nervous system. Anticonvulsant drugs are used to stop a seizure (not to cure epilepsy), however, in some cases, the medication may work so well that no further seizures occur as long as it is taken.

Although the neurologist may have an accurate picture of a persons seizures, sometimes the drugs that are prescribed do not work. "Determining the correct drug, combination of drugs, and proper dosages for a given patient is sometimes a difficult and time-consuming process. In general, the neurologist starts with prescribing the one drug that most effectively controls the particular seizure type the patient is experiencing, in a dosage that the majority of patients of the same height and weight as the patient tend to tolerate well. To prevent the occurance of major seizures in patients with petit mal, the neurologist can give a grand mal type anticonvulsant also. When the patient experiences further seizures, the drug dosages are increased gradually until the seizures stop or side effects occur. In the latter instance, the dosage is then reduced slightly so that the side effects disappear, and another anticonvulsant drug, specific for a patient's seizure type, is added. Depending on the severity of the patient's seizure disorder, this process has to be repeated for months or years. If the patient has serious behavioral disturbances in addition to epilepsy, tranquilizing medications may have to be prescribed along with anticonvulsants." (Epilepsy Rehabilitation, 1975)

According to the Epilepsy Foundation of America, parents of young children should be aware of the following:

* Early recognition of seizures and regular consistent treatment with anticonvulsant drugs offers the best chance of a normal childhood and a positive future for the child with epilepsy.

* As children grow and increase in weight, the original dose of anticonvulsant drugs may no longer be effective in preventing seizures. That is why regular check-ups are important even when the child is doing well and having no further seizures.

* Because of the many physical changes that take place as the child grows, it is not unusual for a seizure-free child to suddenly begin having seizures again. This does not mean the medication is not working or that the condition is getting worse; usually a change of dosage by the doctor will take care of the problem.

* Because of the differences in the way in which the physical systems of children and adults process drugs, it takes a relatively larger dose of anticonvulsant to control seizures in the average child than in the average adult. At the onset of puberty (adolescence), body chemistry changes over from that of childhood to adulthood. It can happen in a matter of months. Unless the drug levels are tested and the dosage adjusted accordingly, the newly-matured adolescent will suddenly find himself taking more medication than his system can handle. He may become drowsy and find it difficult to do school work. It is, therefore, important for youngsters on anticonvulsants who are approaching sexual maturity to have checkups and drug level tests periodically so that overmedication can be avoided.

* Children should be encouraged as early as possible to be responsible for taking their own medicine. In most cases this will give them a grown-up feeling and a sense of being in control of their condition. The decision on when to allocate complete responsibility to the child should be based on his or her maturity and intelligence level.

* If medication is being given in liquid form (in which particles of the drug are already pulverized and mixed in a syrup), the bottle should be shaken well before the dose is poured. Otherwise the effective part of the drug may sink to the bottom, making the first doses out of the bottle too weak and the last ones too strong.

* In some children, phenobarbitol may have the effect of producing hyperactive, irritable behavior. In other children, performance ability may be impaired. If these problems arise at home or at school, discuss the situation with the physician to see whether a different drug can be prescribed.

* Sometimes the widely used phenytoin (Dilantin) causes gum overgrowth in children. It can be a slight problem or a severe one. It may sometimes be prevented by very careful brushing of the teeth, regular use of dental floss, and frequent professional cleaning by the dentist. If gum growth becomes a severe problem, the tissue can be surgically removed.

* When medication is prescribed for children (or for adults), doctor should be asked whether it should be taken before, during, or after meals. Sometimes medication on an empty stomach can increase the possibility of stomach upset. On the other hand, taking certain medications after food may affect the rate at which the drug enters the bloodstream.

Following is a chart of the drugs normally used in the treatment of Epilepsy and their side effects and usual dosage.

DRUGS USED IN THE TREATMENT OF EPILEPSY *

Average Adult Daily Dose	Name	Side Effects
300 mg.-1.2 gm	CELONTIN *Methsuximide*	Blood dyscrasias, nausea, anorexia (appetite loss), ataxia, rash, drowsiness, dizziness
1.5-20 mg.	CLONOPIN *Clonazepam*	Drowsiness, ataxia, behavior changes, tremor, hair loss, hirsutism (hairiness), anorexia
1750-3000 mg.	DEPAKENE *Valproate*	Gastro-intestinal disturbance, altered bleeding time, liver toxicity
250-1000 mg.	DIAMOX *Acetazolamide*	Numbness of extremities, anorexia, polyuria, drowsiness, confusion
100-400 mg.	DILANTIN *Phenytoin*	Ataxia, insomnia, motor twitching, nausea, rash, gingival hyperplasia (gum overgrowth), hirsutism
100-800 mg.	GEMONIL *Metharbital*	Gastric distress, dizziness, irritability, rash, drowsiness
400-600 mg.	MEBARAL *Mephobarbital*	Dizziness, headache, nausea, facial edema, skin rash
0.2-0.6 gm.	MESANTOIN *Mephenytoin*	Blood dyscrasias, skin rashes, ataxia, diplopia (double vision), tremor, drowsiness
250-1000 mg.	MYSOLINE *Primidone*	Ataxia, vertigo, anorexia, fatigues, drowsiness, hyperirritability
600 mg.-2.4 gm.	PARADIONE *Paramethadione*	Nausea, anorexia, insomnia, diplopia, skin rash, bleeding gums, blood dyscrasias
2-3 gm.	PEGANONE *Ethotoin*	Nausea, fatigue, insomnia, diplopia, skin rash, fever, headache, dizziness, numbness
100 mg.	PHENOBARBITAL *Phenobarbital*	Drowsiness, irritability
2-3 gm.	PHENURONE *Phenacemide*	Anorexia, drowsiness, insomnia, psychic changes, hepatitis, nephritis, blood dyscrasias
600-1200 mg.	TEGRETOL *Carbamazepine*	Dizziness, drowsiness, blurred vission, nausea, anorexia, skin rashes, blood dyscrasias
15-45 mg.	TRANXENE *Clorazepate*	Drowsiness, fatigue, ataxia, depression, headache, tremor
600 mg., 2-4 gm.	TRIDIONE *Trimethadione*	Nausea, anorexia, insomnia, diplopia, skin rash, bleeding gums, blood dyscrasias
4-40 mg.	VALIUM *Diazepam*	Drowsiness, fatigue, ataxia, depression, headache, tremor
500 mg.-1.5 gm.	ZARONTIN *Ethosuximide*	Anorexia, nausea, drowsiness, headache, dizziness, fatigue

*Adapted from the Tri-State Epilepsy Association Drug Chart (Tri-State Epilepsy Assoc.)

An additional anticonvulsant drug is Depakote (Valproic acid). Some of its possible side effects are indigestion, nausea, vomiting, stomach or intestinal cramps, diarrhea, drowsiness, dizziness, fatigue, and headache.

What Are Side Effects?

Most drugs besides their therapeutic effects have undesired effects, which are called side effects. In treatment we usually try to take advantage of the therapeutic effects, avoiding or minimizing side effects as far as possible. However, drugs are unaware of our purposes, and produce their side effects whether we want them or not.

Are Side Effects Always Harmful?

No, not necessarily. This is especially so if the side effects are very mild. Some cause no directly recognizable symptoms and can be detected only by laboratory tests. In other cases the symptoms can be so mild they are of no consequence. Sedation is a common side effect of some anticonvulsants. Overgrowth of body hair sometimes caused by Dilantin is usually of no concern to males but may be a major cosmetic problem for females.

When Are Side Effects Most Likely to Occur?

Most drug effects, including side effects, are dose dependent; that is, as the dose is increased the side effects increase. As the does is decreased the side effects decrease and usually to away when you stop taking the drug. Thus you should be alert whenever the dose of your drugs is changed, and especially when increased.

Most drugs can interact with each other to produce side effects that would not occur if you were only taking one of the drugs. It is important to remember that any medicines you take for any other problems you may have can cause these interactions. This applies also to non-prescription "over-the-counter" remedies, especially if taken for longer than two days.

What Are The Most Common Side Effects Of The Anticonvulsant Drugs

The list that follows is not complete but includes the more common side effects most likely to be encountered.

Sedation (may experience tiredness or lack of enthusiasm)
Disturbance of Coordination (double vision, slurred speech, etc.)
Stomach Upsets
Skin Rashes
Blood Dyscrasias (prolonged bleeding, easy and extensive bruising, persistent sore throats or other infections that don't heal.)
Vitamin Deficiencies
Gum Swelling

(taken from 10/84 revision of a 1978 "mini-paper" of the Epilepsy Foundation of America)

Surgery

"Surgery to remove an epileptic focus in the brain is sometimes successful in preventing seizures in patients whose epilepsy cannot be controlled by drugs. In deciding which patients may benefit, surgeons will consider the location of the brain area involved and its important in everyday behavior. Neurosurgeons will avoid operating in areas of the brain that will interfere with speech, language, hearing or other major faculties." (National Institutes of Health)

Special Diets

"If seizures are hard to control with all the usual drugs, or if for some reason a child cannot tolerate standard medication, a *ketogenic* diet may be tried. This diet is designed to make a change in the body's basic chemistry. It is very high in calories and fat, and produces a condition called ketosis. In some children this has the effect of preventing seizures.

An experimental variation of the diet was developed recently. It is called the *medium chain triglyceride (MCT)* diet. It produces a ketogenic effect by the addition of a special oil to the child's diet. The oil is measured out according to the child's consumption of other foods. It may be taken on a spoon or, if the child balks, may be added to ordinary food. This form of the diet is less disruptive to family eating patterns, since the child can eat most foods as long as he also takes enough of the special oil." (Epilepsy: You and Your Child, 1983)

Psychological Approach

"One psychological approach to treat epilepsy involves training patients in methods that might allow them to control their brain waves. In the experimental technique called biofeedback, patients learn to correlate

brain cell activity with visual images or sounds that are provided. They try to modify the sights or sounds and in this way alter the electrical activity in the brain. Biofeedback appears to help some patients, but how or why it does remain tantalizing questions." (National Institutes of Health)

Summary

Although a person with epilepsy may have his physical symptoms under control, he may still be fearful about having another seizure. This fear can be diffused in many cases by seeking counseling, not only for the person with epilepsy, but for all members of the family. The stigma that is usually attached to epilepsy may affect a person with epilepsy and/or family or friends in different ways. In order to fully understand and be aware of the psychological reprocussions a person may suffer, we need to look at the following cultural values that are considered to be positive attributes in our society: (Epilepsy and the School Age Child," 1977)

"1. INDEPENDENCE: No one is completely independent. However, this quality is highly prized in our culture, and most people like to think of themselves as independent. A person with epilepsy can be made to feel dependent by daily medications, frequent doctor visits, restriction from certain employment opportunities, sometimes being unable to get a driver's license, and perhaps by the need to rely on total strangers for help during a seizure.

2. BEAUTY: During most seizures the person simply does not look nice. Students are very conscious, as we all are, of accepted standards of beauty or attractiveness. To fall short of these standards, even if only during brief seizures, may be socially painful.

3. SELF-CONTROL: Most of us want to feel and appear in control of ourselves and our situation. During a seizure all semblance of self-control

is lost. This can be frightening to the observer as well as to the person with epilepsy.

4. HEALTH: The frequent use of the words "health and happiness" together, as if they were synonymous, reflects how highly we prize health. A child with epilepsy is usually as healthy as other children, but epilepsy is often thought of as an illness and viewed negativley.

5. PERFECTION: Many times people forget that this quality is not enjoyed by anyone. To the extent that parents, children, or school personnel may view epilepsy as a sign of imperfection, epilepsy becomes a burden."

SOME SUGGESTIONS:

- Accept the child (person) unconditionally, despite the standards he does not appear to meet.
- Help him to understand his limitations.
- Allow him to learn from his mistakes (through experiencing).
- Allow him age-approprate responsibilities.
- Teach him to be responsible for the management of his disorder. (Taking medications and making decisions about his disorder.)

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LEARNING DISABILITIES

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LEARNING DISABILITIES
(Sometimes called the invisable disability)

The term "learning disabilities" is used to describe a handicapping condition that interferes with a persons ability to store, process or produce information. The impairment can be subtle and go undetected throughout life or it may create such a gap between a person's capacity and his actual functioning that it becomes necessary to intervene with an adjusted educational program.

Definition

The Education for All Handicapped Children Act carefully defines this specific group as follows:

> *"Specific learning disability means a disorder in one or more of the basic psychological processes involved in understanding or in using language, spoken or written, which may manifest itself in an imperfect ability to listen, think, speak, read, write, spell, or to do mathematical calculations. The term includes such conditions as perceptual handicaps, brain injury, minimal brain dysfunction, dyslexia, and developmental aphasia. The term does not include children who have learning problems which are primarily the result of visual, hearing, or motor handicaps, of mental retardation, or of environmental, cultural, or economic disadvantage." (Section 5 (b) (4) of P.L. 94-142)*

There are many other definitions used and accepted by professionals in the field. The authors of these definitions have basically the same intent - to define learning disabilities in such a way as to organize necessary services.

There are four basic dimensions across most definitions:

1. There is a discrepancy between the expected performance and the actual performance of the child.
2. Behavioral manifestations are indicated in academic and language areas of strengths and weaknesses in learning.
3. There is an absence of other complications, such as deafness and visual problems.
4. There is a focus or primary explanation for the particular learning problem.

A learning disability is not always immediately obvious. Because one of the basic dimensions of most definitions is a discrepancy or gap between a child's expected and actual achievement, the child may not be identified as having a learning problem until he is beginning school or well after he is in the academic setting.

The child with a learning disability is usually first identified as an under-achiever and exhibits a disorder in listening, thinking, talking, reading, writing, spelling, or arithmetic. Once the child has been identified as having one of the above disorders and a deficiency in achievement, he is usually evaluated through standardized achievement tests and individual intelligence tests to establish the discrepancy. (See page 80)

Most typical of children with learning disabilities is an average or above average I.Q. with problems in a particular area of achievement. Within that area (math, reading, etc.) it is then necessary to pinpoint the specific skill deficiencies.

Confusions related to learning disabilities:

1. Any number of terms have been used when describing a child with a learning problem. These terms will vary depending on where a person lives and the academic discipline of the professional doing the diagnosis. The following terms are but a few of those used to label children. This variation in terminology contributes to the confusions related to learning disabilities.

learning disabilities	diffuse brain damage
aggressive behavior disorder	disorders of impulse control
brain dysfunction	disorders of motor coordination
brain injured	disorders of perception
cerebral dysfunction	dyslexic
character impulse disorder	hyperkinetic behavior disorder
clumsy child syndrome	hyperkinetic impulse syhdrome
conceptually handicapped	mild neurosatory deficit
attention disorder	minimal brain dysfunction
minimal brain injury	minimal cerebral damage
minimal cerebral dysfunction	minimal cerebral injury
minor brain damage	minimal chronic brain damage syndrome

neurologically handicapped	neurophrenia
organic behavior disorder	organic brain damage
perceptually impaired	perceptually handicapped
specific learning disabilities	psychoneurological learning disabilities
visual-motor perceptual lag	

(Listing taken from: The Learning Disabled Child, McWhirter)

2. Parents are many times frustrated and confused because their child exhibits inconsistent behavior. "The behaviors and problems which typify one learning disabled child may be totally different from the behaviors and problems of another learning disabled child. In some instances even the problem behavior of one child may not be consistent." (The Learning Disabled Child, McWhirter)

3. Professionals in the field of learning disabilities often do not agree among themselves as to the cause (etiology) of the learning problem and what methods of treatment are required. Frequently these decisions are based on theories and not on facts. Many times it is not known how the problem occurs or what exactly is involved (physiologically and/or psychologically).

4. Sometimes confusions arise from a lack of understanding about the child's learning problem and from a lack of good, clear information from professionals.

Types (a partial listing taken from "The Medical Forum," Sept. 1984)

"Attention: By far the most common kind of learning disorder is difficulty in keeping attention focused. One 14-year-old boy described his problem this way: "Doc, I'll tell you just what my head is like. It's like a television set. Only one thing: it's got no channel selector. You see, all the programs keep coming over my screen at the same time." Because these children keep tuning in and out, their performance is unbelievably and confusingly inconsistent. They might do well one minute and poorly the next, or have one good week in school followed by another that is disastrous. They might

be able to do a math problem on Thursday but fail to solve it on Friday. Because they've been caught doing something well once in a while, people keep accusing them of not really trying the rest of the time. These children may be overactive, but some have perfectly normal activity levels, and some are even lethargic. They are likely to be impulsive, to do things too quickly, and get into trouble because they haven't thought through the risks they take. They are often described as emotionally disturbed, and the parents may be blamed, whereas everyone is really an innocent victim of a subtle handicap affecting the way the child's brain organizes his ability to concentrate.

As these children get older, they may be great at grasping the big picture and understanding overall conceptions. They often have rich imaginations and are extremely creative--even as they fail all their subjects in school because they can't easily focus on other people's details. If they are not damaged by too much criticism early in life, these children may blossom into incredible adults. But they tend to accumulate a negative self-image as "losers." They're accused of various forms of moral turpitude: laziness, poor motivation, and so on. But we know they're not lazy from observation and testing. We find that they have real trouble focusing and may fatigue very rapidly when they try to concentrate.

Attention deficits are not only the most common sort of disability, they also frequently are associated with other types of learning disorder.

Language: Some people are very good at understanding things that they see but have real difficulty interpreting complicated verbal instructions, remembering things they've heard, or expressing themselves in language. They have trouble with reading comprehension and may not be able to grasp and follow spoken directions. Sometimes they develop behavior problems because they're so embarrassed about their disorientation. When they can't keep up with other children on a verbal level, some develop terrible social problems including delinquency.

Spatial orientation: Other children are just the opposite--terrific with language but hard-put to process information visually. They may be confused about where things are around them. This handicap sometimes shows up as poor reading or spelling, because the affected child has trouble remembering how words look and tends to reverse similar script letters, such as *p* and *g* or *b* and *d*.

Memory: Another group of children has real difficulty with retrieving information from memory--not all information, but certain specific kinds. This problem becomes more noticeable as the child gets older, because the upper grades increasingly require rapid recall of stored information. If you can't find what you need, and quickly, you're in trouble.

Fine motor control: A whole series of problems can interfere with the coordination of fine muscular movement, and thus with handwriting. Affected children can't quite remember how to form letters quickly and easily enough, or they have trouble controlling the pencil. The child may be extremely bright and have excellent ideas, but there's

a complete breakdown between his head and the paper. Somehow the good material gets lost in the process of writing, and he becomes ashamed of what he has produced.

Sequencing: A great deal of school depends on a child's ability to understand or perform a series of items in correct order. Children who get mixed up about the sequence may be able to keep only two or three things straight before the task unravels. They have difficulty following instruction; they may have trouble with math; they can't organize their time. Often, when they're young, they are slow to learn the days of the week and the months of the year. Later on, telling time may be difficult for them. When they get into secondary school, they are disorganized and may find if difficult to remember the order of their classes."

Causes

As mentioned above, children with learning problems are usually discovered in the academic settings. The fact that a child can do some tasks or skills very well and have problems with others is very confusing to parents as well as professionals. Because one of the criteria for identification of a learning disability is the discrepancy factor, it becomes necessary to first consider some possible causes associated with a child's education (Learning Disabilities, 1979)

- Inappropriate Teaching
    a. Child may never have been taught;
    b. Teacher may not have developed the necessary skills to teach the basic school subjects;
    c. Teacher expectations may be too high or too low (knowledge acquired in school files sometimes causes some teachers to limit their instruction and expectations for some children).

- Inadequate Instruction

  a. Child may not have developed the necessary prerequisite skills for their level of instruction (may have been moved along to quickly);

  b. Poor instructional programming and design;

  c. Lack of motivating activities;

  d. Narrow curricular content (no direct instruction in social skills, physical or motor learning, and oral language abilities - talking, interacting, using bodies in purposeful fashion).

- Inappropriate methods, materials and curriculum

  a. For example, a reading series may not provide for cultural diversity (may be unlike a child's natural environment);

  b. Motivation and self-concept can both be adversely affected.

Environmental Factors

Nutrition, Health and Safety

- Basic hunger may affect a child's motivation, attention, and application to a task;

- The amount and kind of a child's nutritional intake has led to increased interest in megavitamins;

- Food additives (especially synthetic colors and flavors) may contribute to hyperactivity in some children (Feingold);

- The maternal diet during pregnancy is an area of concern;

- The general health of a child may be involved in learning disabilities (chronic colds, respiratory problems and allergies);

- A child's physical safety may be related (falls, brain injury, head traumas, etc., appear in clinical records of learning disabled children.)

Sensory Stimulation

- A child needs the input of his senses to learn how to learn;

- The amount and kind of sensory stimulation is important in later learning (early stimulation and sufficient variety effect the child cumulatively).

Language Stimulation

- Adequate models for language development are needed in order to appropriately learn other skills;
- The amount and kind of linguistic activities for good verbal language abilities are needed;
- Children with learning disabilities may need enriched language experiences to help develop the needed language abilities.

Emotional and Social Development

- Some children with learning disabilities may exhibit coping and compensating behaviors that interfere with learning;
- A child needs to approach learning with self-confidence and enthusiasm;
- Some exhibited behaviors (anxious, insecure, impulsive, and unruly) may be related to a lack of natural security, consistency, love, warmth and acceptance.

Psychological Factors

- A child with learning disabilities may exhibit disorders in perception (may not be able to understand directions), recall (may not remember something recently taught), and conceptualization (may not be able to organize things in a meaningful way or appropriate order).
- Sometimes there is a presence of the following learning deficits:
  a. poor visual or auditory perception and discrimination;
  b. slow understanding and interpretation of concepts;
  c. poor organizing and generalizing ability;
  d. inability to express concepts;
  e. minimal motor and verbal skills;
  f. poor short-term memory;
  g. poor closure (Kirk & Kirk, 1971).

- Some cognitive theorists believe that some behaviors, such as impulsivity (difficulty in inhibiting motor movements, distractibility, and inattention) may be caused by an impulsive cognitive tempo or disposition (Epstein, Hallahan, and Kauffman, 1975).

- Some causes of another related behavior, hyperactivity, may be associated with a neurological impairment, the nature and extent of motor activity may interfere with the accurate assimilation of information, or the child may react too impulsively to tasks and problems. (Keogh, 1971)

Physiological Factors

- Brain injury

- Damage to the central nervous system

Genetic Factors

- Some learning disabilities may be inherited (a high probability that specific dyslexia is a genetic disorder - Hallagren, 1956).

Biochemical Factors

- Researchers suggest that various metabolic disorders may be linked to learning diabilities

  1. hypoglycemia (Cott, 1972; Green & Perlman, 1971);

  2. imbalance of acetylcholinesterose (Smith & Carrigan, 1959);

  3. hypothyroidism (Money & Lewis, 1964);

  4. deficiency of GABA (inhibitory chemical transducer - genetically transmitted);

- Medications

  1. Ritalin and Dexedrine are the most frequently used drugs;

     - sometimes used to control impulsivity, aggressive and inattentive behaviors.

Pre-, Peri, and Postnatal Factors

- Factors associated with prenatal neurological damage and later learning problems (Pasamanick & Knoblock, 1973)

  "1. Maternal-fetal blood type incompatabilities (Rh factor)

  2. Maternal endocrine disorders (hypothyroidism, diabetes, etc.)

3. Radiation
4. Maternal age, reproductive readiness, and efficiency
5. Drugs
6. Rubella
7. Anoxia
8. Maternal cigarette smoking
9. Prematurity
10. Accidents"

- Postnatal Factors
  1. Head injuries
  2. Lead poisoning causing neurological damage
  3. Nutritional deficits (hypothesized)
  4. Sensory deprivation (Hallahan & Cruickshank, 1973)
  5. Food additives (Feingold, 1976)

Maturational Lag

- Immaturity (may be related to a lag in the maturation of some central nervous system components - Bender (1968), Hirsh, Jansky & Langford (1965), Silver & Hagen (1960).

Minimal Brain Dysfunction

Studies indicate that there exists a significant difference of opinion as to whether there is a link between some kinds of brain injury or central nervous dysfunction and children with learning disabilities.

Some children with learning disabilities may show measurable brain damage while others will not.

General Characteristics

- Associations - difficulty in categorizing, conceptualizing or drawing conclusions;
- Attention span - held only for short periods of time;
- Awareness - unable to keep pace;
- Confusion - easily confused and mixed up;
- Demands constant attention - excessively especially from adults;
- Destructive;
- Developmental immaturity - slow during first few years;
- Directionality - confusion of concepts of right to left, up & down, etc.
- Distractibility - may not be able to block out minor distractions;
- Hyperkinesis - frequently in state of constant motion;
- Perseveration - repeating, unable to shift from one activity to another;
- Retention - may remember one day but not the next.

Visual Perceptual Characteristics

- Arithmetic - may be good at computational or oral math problems, but not with word problems;
- Comprehension & Reading - may not comprehend sequencing exercises, putting comic strips together in order, etc. Unable to see relationships;
- Discrimination - difficulty in telling the difference between shapes (square, circle, etc.) Related to problems in differentiating between letter shapes;
- Figure-Ground Problems - cannot find hidden things in pictures or may overlook obvious and fixate on nonessential detail;
- Letter Confusion - may confuse letters when reading or writing (*m* for *n*, *b* for *d*, *+* for *1*, etc.);
- Order - frequently loses place when reading;

- Organization - may reorganize letters in words while reading (*spilt* for *split* or *read* for *dear*, etc.);
- Reversals - may reverse words, letters, or numbers (*was* for *saw*, *b* for *d*, or *29* for *92*);
- Transfer of Training - cannot transfer ideas or thoughts from one situation or context to another;
- Visual Memory - poor visual memory recognition; may not remember a picture when removed.

Auditory Perceptual Characteristics

- Auditory Association - may not be able to associate the word *car* with a picture of a car or may have difficulty associating sounds of letters with the appropriate symbols;
- Auditory Memory - cannot repeat series of digits, may forget easily what he has been told;
- Auditory Sequencing - unable to arrange in order;
- Consonant Sounds - may not hear a specific letter sound in words or recognize the beginning, middle and ending sounds in words;
- Expression - difficulty in expressing and organizing thoughts;
- Following Directions - unable to comprehend directions and is easily confused;
- Interpretations - may misinterpret a word or phrase;
- Reading - may have (or not have) a mild to severe reading handicap and may be unable to read aloud in a group;
- Rhyming - cannot discriminate between rhyming words or be able to tell which words rhyme and which words don't;
- Sound Discrimination - confuses words like *dig* and *day*, or *lip* and *dip*), cannot hear letters or cannot tell difference between letters (such as *b* and *d*);
- Sound Blending - unable to sound out words and/or put the sounds together into a meaningful word.

Perceptual Motor Characteristics

- Ataxia - uncoordinated and clumsy;
- Auditory-Motor Lag - may be a time lag between when the child is told something to do and when he actually makes the appropriate response;

- Eye-Hand Coordination - unable to throw and catch a ball, problems staying within the lines while coloring, etc.
- Fine Motor Coordination - difficulty in drawing, letters poorly formed, clumsy with scisssors, problems with shoe laces, buttons, zippers, etc.

A child with learning disabilities may be expected to exhibit one or more characteristics from one or more of the above categories. The behaviors that result from these characteristic areas of learning have a direct influence on a child's ability to function in an academic setting.

Some children with learning disabilities have been characterized as being "hyperactive." Although this does not include all learning disabled children, it does warrant a short description.

Hyperactivity

A child is usually described as being hyperactive when his motor activity level is above what is considered normal. The following behaviors are usually characteristics of a child who is hyperactive:

- attention cannot focus on any one stimulus, may shift attention from one thing to another, to another, etc;
- May exhibit inappropriate motor behavior;
- Usually in perpetual motion;
- When talking, he may ramble from one subject to another;
- May exhibit disturbances in sleep patterns, may arise frequently in the night and/or sleep at one time one day and another time the next;
- Child may not need or want much comforting.

Medication can be obtained from a family physician after a thorough examination. Ritalin and Dexedrine are the most commonly used drugs.

These are stimulant drugs that have a calming affect when used on children.

Children with hyperactivity will also respond to whatever is happening to his environment.

By setting a relaxed atmosphere it can help the child adjust, and respond appropriately to, his environment.

Recommendations for Parents (taken from: Does Your Child Have A Learning Disability?, 1974)

Discipline

- Parents of a learning disabled child should approach discipline as they would in dealing with a *normal* child. All children need discipline with respect to having limits set on their behavior. By establishing limits on behavior, the child knows how far he can go and what he may or may not do. The key to successful discipline lies in consistency, not severity.
    - Discipline should encourage a child in doing what is expected of him.
    - Discipline should be handled with kindness and in a quiet, firm manner.
    - The need for rules should be discussed with the child before they are established.
    - The consequences of rule violation should also be discussed with the child so that he is aware of the penalties.

Completing a Task

- A child should be praised for any sustained attention directed towards a task.
- Once a project is completed, the child should be rewarded.
- Rewards do not have to be tangible, attention from an interested adult can be the most potent reward.

Establishing a Routine

- Doing the same things at the same time and in the same way will help the child establish a set of familiar behaviors from which to derive security.
- The child may benefit from having an established routine for:
    - Awakening in the morning. If the child arises at the same time every morning it will become easier for him to do so.

- Eating at the same time every day. The meal should be a relaxing experience with a minimal amount of turmoil. Some children will benefit from having the table uncluttered. Non-essentials should be removed from the table.

- Dressing should be made relatively simple. Allow plenty of time for the child to get dressed. Clothing which is easy to put on and take off should be selected. If the child has problems using snaps, select clothing which has large, easy to use buttons. Encourage the child to choose his own clothes. Children who have difficulty selecting appropriate articles may find a color tag or number system helpful.

- The child should be expected to perform household chores which are appropriate for his age. These chores serve to make the child feel that he is a part of the family and capable of carrying his end of the load. Tasks successfully completed increase the child's self-esteem and give him a sense of accomplishment. When siblings alternate chores, the learning disabled child can be included in those activities he is capable of performing

Visual guides can be useful if a child is having difficulty remembering (a picture can aid in remembering order, structure, etc.).

Following Directions

Children who have difficulty remembering directions should be given them one at a time. After the child has successfully completed the first task, he should be given the second set of directions. A child who has a short auditory memory or poor sequencing ability becomes easily confused when several sets of directions are presented at one time. By the time the third set of instructions is given, the child has already confused, distorted or even forgotten the first two.

Give one set of directions at a time. Have the child *explain* them to you. Repeating them back verbatim is no sure sign that they know what to do, only that they remembered what you said. Some children may require that the parents model or demonstrate the desired response several times before they comprehend what is expected of them. Complex tasks should be broken down into simple components and taken one at a time.

Length of Work Assignment

The length of a work assignment, homework session, etc., depends upon the age and maturity of the child. Children who have difficulty with a sustained activity should be given

assignments which last five to ten minutes at one session. This time may be too much for some and not enough for others, but it is a starting point.

As the child's ability to attend to what he is doing improves, the length of the task can be increased gradually. The child's interest, motivation and level of confidence are critical factors which relate directly to his performance. Rewards can be a positive influence in developing these inner controls.

Remediation

"Presently, there are several philosophies regarding the remediation of children with learning disabilities. Some of the more prominent techniques include:

- Motor Training: Motor activity of the fetus can be experienced during pregnancy. The young infant engages in a lot of random motor or movement activity. As the infant matures, his movement patterns become more sophisticated. Motoric behavior directly affects our ability to physically respond to and deal with events in our environment. In addition, our concept of ourselves as either a competent or incompetent person is determined, in part, by how well we respond to our physical environment. The child who is clumsy, awkward, uncoordinated and constantly trips over himself is going to develop a different frame of reference about his world than the child whose motor actions are fluid and well integrated. Children who exhibit poor locomotion, coordination, etc., are in need of developmental motor training.

- Neurological Integration: Neurological integration is developmentally progressive. In order for the higher processes to predominate, the lower level processes must mature. Myelinization, reflexive behavior, subcortical development and cortical dominance are sequentially progressive in a developmental hierarchy. A child who has not experienced sequential organization due to developmental disorders or physical trauma, will experience learning difficulties.

- Visual Perceptual Training: Visual perceptual training incorporates specific visuo-motor activities in an attempt to train the eye. Ocular motor activities are designed to facilitate movement patterns of the eye. Eye-hand coordination activities and visual imagery training attempt to remediate learning problems involving poor visual perceptual development. Training includes activities for improving figure-ground discrimination, spatial awareness, visual constancy, imagery and visuo-motor development.

- Language Development: Language development involves the individual's ability to communicate effectively. This communication process is dependent upon the ability of the person to receive, process and express information in a

meaningful, orderly way. Children who experience communicative disorders are impaired educationally. Training activities attempt to help the child gather information from the environment, interpret this information and respond appropriately to it.

All of these programs have common elements, and each provides a basis for establishing a suitable, remedial program. No single approach can stand by itself as the sole technique for providing remediation to all learning disabled children. (Taken from: Does Your Child Have A Learning Disability? Stephen W. Freeman Ed.D.)

SUMMARY

1. Learning disabilities affect children with average, above average, and even superior intelligence.
2. Learning disabilities affect approximately 10 percent of school population.
3. The incidence is higher among boys.
4. A learning disability is not the same as mental retardation or mental illness.
5. There is a great variety of opinions on the causes of a learning disability. These are still being investigated and researched.
6. All persons with learning disabilities are different. The one trait that they do have in common is that they perform well below their actual ability level.

TESTS

INTELLIGENCE

- *Stanford-Binet Intelligence Scale.* The Stanford Binet, a norm-referenced standardized measure of general intelligence, is an individual test appropriate for persons aged 2 through adult. The Stanford-Binet consists of a series of tasks arranged by age.

  Test tasks differ by age. For example, at the 2-year level, the subject is asked to build a tower of blocks and identify parts of the body; at the 6-year level, the subject must define words and solve a maze. According to Sattler (1965), seven areas are tapped by the Stanford-Binet: language, memory, conceptual thinking, reasoning, numerical reasoning, visual-motor, and social intelligence.

  Two scores result from the Stanford-Binet, the mental age (MA) and the intelligence quotient (IQ). MA is an age score; IQ is a standard score,

- *Wechsler Intelligence Scale for Children--Revised.* Like the Stanford-Binet, the WISC-R is a norm-referenced standardized measure. It is administered individually and is appropriate for persons aged 6.0 to 16.11.

  In contrast to the Binet, the WISC-R is organized by subtests rather than by age levels, all individuals who take the WISC-R are given the same type of tasks. Subtests are of two types, verbal and performance. On verbal subtests the subject listens to questions and replies orally, and on performance subtests the subject performs visual-motor tasks. There are a total to ten required subtests, five tapping verbal skills and five performance skills. The WISC, according to Anastasi's review of research (1976), measures four types of ability: general intelligence, verbal comprehension, perceptual-spatial, and memory (or freedom from distractibility).

SPECIAL TESTS FOR HANDICAPS

- *Hiskey-Nebraska Test of Learning Aptitude* (Hiskey, 1966), designed for the deaf and hard of hearing.

- *Blind Learning Aptitude Test* (Newland, 1969).

- *Arthur adaptation of the Leiter International Performance scale* (Arthur, 1950) the *Columbia Mental Maturity Scale* (Burgemeister, Blum, & Lorge, 1972) and the *Raven Progressive Matrices* (Raven, 1977), are tests for nonverbal individuals.

ADAPTIVE BEHAVIOR

- The *Vineland Social Maturity Scale* (Doll, 1965).
- *AAMD Adaptive Behavior Scales.*
- *Adaptive Behavior Inventory for Children,* which is part of the *System of Multicultural Pluralistic Assessment* (Mercer & Lewis, 1977).

("Tests" information taken from: Mental Retardation: From Categories to People)

MEASURES OF ADAPTIVE BEHAVIOR FOR HANDICAPS

Measure	Contents	Age
Behavioral Characteristics Progression, or BCP (1973)	59 areas of objectives (e.g., Feeding/ Eating, Gross Motor, Listening, Adaptive Behaviors, Attention Span)	Mentally and behaviorally exceptional children
Brigance Diagnostic Inventory of Early Development (Brigance, 1978)	Pre-Ambulatory, Gross Motor, Fine Motor, Self-Help, Pre-Speech, Speech and Language, General Knowledge and Comprehension, Readiness, Basic Reading Skills, Manuscript Writing, Math	Through developmental age 7
Cain-Levine Social Competency Scales (Cain, Levine, & Elzey, 1963)	Self-Help, Initiative, Social Skills, Communication	Trainable mentally retarded, ages 5 to 13
Learning Accomplishment Profile, or LAP (Sanford, 1974)	Gross Motor, Fine Motor, Social, Self-Help, Cognition, Language	Handicapped children 3 to 6
Pennsylvania Training Model, Individual Assessment Guide (Somerton & Turner, 1973)	Sensory and Motor, Activities of Daily Living, Communication, Perceptual-Cognitive, Social and Emotional	Severely and profoundly retarded, school age
Preschool Attainment Record (Doll, 1966)	Ambulation, Manipulation, Rapport, Communication, Responsibility, Information, Ideation, Creativity	6 months through 7 years
Project MEMPHIS: Comprehensive Developmental Scale (Quick, Little & Campbell, 1974)	Personal-Social, Gross Motor, Fine Motor Language, Perceptual-Cognitive	Handicapped children ages 3 months to 6 years
TMR Performance Profile for the Severely & Moderately Retarded (DiNola, Kaminsky, & Sternfeld, 1970)	Social Behavior, Self-Care, Communication, Basic Knowledge, Practical Skills, Body Usage	Trainable/severely and moderately retarded
Topeka Assoc. for Retarded Citizens Assessment System or TARC (Sailor & Mix, 1975)	Self-Help Motor, Communication, Social	Severely handicapped age 3 to 16

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AUTISM

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AUTISM

Autism is a label used to describe a set of behaviors or symptoms seen in certain children and adults. Autism is a developmental disability and usually appears during the first three years of life (typically before 18 months). It is four to five times more common in males than females and has been found throughout the world in families of all racial, ethnic and social backgrounds.

Definition (National Society for Autistic Children)

* Disturbances in the rate and appearance of physical, social and language skills.
* Abnormal responses to sensations. Any one or a combination of sight, hearing, touch, pain, balance, smell, taste, and the way a child holds his body are affected.
* Absence of or delays in speech and language, although specific thinking capabilities may be present.
* Abnormal ways of relating to people, objects, places or events.
* Unusual ways of thinking.

A child with autism may show many or all of the symptoms and some children may show only a few. The symptom itself may vary from severe, to moderate, to changeable.

Autism may occur by itself, or it may be associated with other disabilities. About 20-30 percent of autistic children develop seizures and approximately 75 percent have some degree of mental retardation (60 percent of which have I.Q. measurements below 50).

Causes/Theories

No one theory on the cause or causes of autism has been proven to date, but many theories have been disproved and discarded. The following information was taken from "Autism in Adolescents and Adults," 1983.

1. "*The Social-Withdrawal Hypothesis.* Autism was first regarded as an affective disorder. Leo Kanner (1943) considered the possibility of constitutional origins, his major causal emphasis was on parental personality, specifically that parents were emotionally cold, intellectual, and compulsive, all personality traits which encouraged their autistic child to withdraw from social contacts with them. A number of subsequent studies summarized by Cantwell, Baker, and Rutter (1978) presented compelling evidence that parents of autistic children were not significantly different from parents of so-called normal children, with the exception that they had perplexingly handicapped children with needs for special understanding and care. While autism was first thought to be an affective or emotional disorder, it is now widely recognized as a developmental disability (Schopler, Rutter, & Chess, 1979) with a range of handicapping conditions along a continuum of severity (Wing & Gould, 1978).

2. *Parental Social Class Status.* Not only were parental personality characteristics believed to be the primary cause for their child's autistic development, these same characteristics were also thought to be part and parcel of their higher socioeconomic status (SES).

However, as larger samples of families with autistic children were studied, it became evident that these parents also came from middle- and lower-class origins (Ritvo, Cantwell, Johnson, Clements, Benbrook, Slagle, Kelley, & Ritz, 1971; Wing, 1980).

3. *The Single-Disease Hypothesis.* Initially Kanner believed that the autism syndrome indicated a unitary, underlying disease process. This was later widely interpreted to mean that the symptoms were primarily caused by parental pathology. During the last decade research data from diverse sources have shown beyond reasonable doubt that the autistic disorder can be the result of multiple biological causes and nonspecific forms of brain abnormality. For example, Rutter and Lockyer (1967) reported that 18 percent of their follow-up cases had developed seizures at adolescence, when no hard signs of brain malfunction were identified in neurological examinations during the early years. Genetic factors have been demonstrated in a twin study (Folstein & Rutter, 1977). Chess (1977) has shown the rubella virus associated with autism. Darby (1976) found neuropathology, as in cerebral lipidosis and tuberous sclerosis. In short, increasing evidence shows that a variety of biological factors may produce the syndrome of autism.

4. *Autism and Childhood Schizophrenia.* Initially autism was regarded as the earliest form of childhood schizophrenia. However, more recent studies (Rutter & Locker, 1967, DeMyer et. al., 1973) indicate that autism and schizophrenia are very distinct disorders and that most autistic children grow into adulthood without resembling schizophrenia, but more often appearing mentally retarded.

In a study by Kolvin (1971) if was found that most of his autistic subjects had early onset of their disorder before 3 years of age, while

the schizophrenic group was found more frequently with onset during late childhood and adolescence.

5. *Mental Retardation and Peak Skills.* Kanner had first been impressed by the unusual skills, musical abilities, rote memory feats, and number manipulations skills he observed in autistic children. These unusual peak skills were believed to indicate that autistic children had normal or better intellectual potential. This hypothesis was further supported by reports that autistic children were generally "untestable" on standard psychological tests. Alper (1967) and Gittelman and Birch (1967) have shown that autistic children are indeed testable when test items to which they do not respond are replaced by lower level, easier items, and when appropriate, non-language-dependent tests are used (Schopler & Reichler, 1971). Since that time most studies with access to larger samples of autistic children have shown that the majority of cases suffer from severe to mild degrees of retardation (DeMyer et al., 1974; Schopler, Andrews, and Strupp, 1979)..." By now it is widely accepted that autism and mental retardation coexist and are not necessarily different diagnostic categories (Rutter, 1978)."

"Scientific evidence indicates that the symptoms which make up the autistic syndrome are caused by a subtle form of brain damage occurring before, during, or shortly after birth, and that this damage is a result of metabolic, infectious, genetic or other disease activity including perinatal cardiorespiratory distress. There is also a suggestion that chemical insult could result in the same sort of damage to developing brain structures." (National Society for Autistic Children)

Prevalence

Autism occurs in approximately 4 to 5 of every 10,000 births. If a person exhibits some but not all of the behavorial symptoms, the incident rate triples. In Michigan, there are from 4,600 to 13,800 children and adults with autism or autistic-like symptoms (Michigan Society for Autistic Children).

Treatment

Currently there is no cure for autism, however, through behavior modification techniques much has been done to help the autistic child. Autistic behavior is fairly easy to recognize and by focusing in on inappropriate behaviors, some can be eliminated and others reduced. Behavior management is a systematic and structured way to inculcate habits that will enable a child to live more comfortably with others. Much behavior management is carried on in the home, usually concerned with social behavior (ranging from toilet training to modification of repetitive and mechanical behavior).

Another aspect of behavior management takes place in the school (Special Education) and focuses on language, self-help skills, and prevocational training.

"The severe form of the syndrome may include the most extreme forms of self-injurious, repetitive, highly unusual, and aggressive behaviors. Such behaviors may be persistent and highly resistant to change, often requiring unique management, treatment, or teaching strategies.

Supportive counseling may be helpful for families with autistic members, as it is for families who have members with other severe life-

long disabilities. Medication to decrease specific symptoms may help certain autistic people live more satisfactory lives." (Michigan Society for Autistic Children; "A Short Definition of Autism")

The World Experienced by the Autistic Child ("Autistic Children--A Guide for Parents and Professionals")

* "Some never speak. Others learn a few words, almost always later than usual. They show typical but unusual patterns of speech. Some try to communicate by repeating what they have just heard; this is called echolalia. If you ask "Do you want a cookie?" and the child answers "Do you want a cookie," the chances are that he wants one. Some show delayed echolalia and are able to repeat verbatim something heard in the past. Some have a great repertory of television commericals. Some learn to say meaningful words and phrases of their own, but sentences may be abbreviated, words confused and collapsed, letters reversed within words, or words within sentences. They have trouble with prepositions and pronouns, confusing "you" with "I." Some talk quite successfully but express themselves like a telegram. Others learn to talk fluently and correctly about a wide range of subjects.
* They have trouble with pronounciation and voice tone. They miss ends of words or use only pieces and frequently cannot produce a smooth flow of words. Correct vocal inflection is rare.
* The way they see often seems to be as confused as the way they hear. They may be fascinated by shiny objects, upset by bright lights, or look at an object only when it is moving. They appear

to recognize shapes only by the general outline, suggesting they may not be using the part of the eye that sees fine detail. They tend to be confused by complicated and rapidly changing sights.

* Autistic children do not seem able to communicate with gestures to show what they want, though they will often push your arms towards something they want. They may have to be taught to point and to smile.

* They often learn about the world not so much by seeing and hearing as by using touch and smell and taste to explore. They may enjoy games that provide what neurologists call vestibular stimulation, like being tossed in the air, even though they don't otherwise like being touched. Some appear insensitive to cold, heat or pain, or very sensitive, or they may alternate between the extremes.

* Many have unusual body movements: walking on tip-toe, flapping hands and arms, rocking back and forth in a chair, or spinning around without becoming dizzy. When a child is meaningfully occupied these movements tend to disappear. Their movements are immature, though some may be skillful climbers and balancers. They have trouble copying movements like hopping and skipping. They may confuse back and front, left and right."

Conclusion

Parents of autistic children are faced with a very unique and sometimes devastating problems; what to do with a nonrelating autistic child. Family pressures can sometimes escalate into a full-blown crisis situation. Learning to cope and survive are essential. The following thoughts and feelings were written by Ron and Penny Schneider (Saginaw, MI), parents of two autistic children:

*** "February 22, 1962, was by far the most exciting day of my young life. At age 23 I had actually done it. I was a father. It is really difficult to understand what that means; the hopes, the dreams, an All American quarterback, if you have never experienced it. Never mind that he is only 19 inches long and weighs six pounds ten ounces. The world is his for the asking. After all, if he's not a great athlete he will certainly be, at least, a distinguished doctor, lawyer, engineer, or whatever. More importantly, he is successfully going to take his place in this world. He can't miss. He is my son!

His delivery wasn't exactly normal; long labor, instruments, some facial bruises, but he was here, a living extension of two people who loved each other and, more importantly, wanted and loved what they had miraculously created. The thought that he may not be normal never entered our minds. That only happens to other people.

As time progressed, however, it became more apparent that he would not be normal. The dreams and hopes began to slowly fade and were replaced by anxiety and fear of the future.

A steady procession of doctors and clinics followed with no answers and in most cases not even the guts to tell you there weren't any! It was much easier to be told, "he will probably grow out of it." In addition, medical bills begin to mount further compounding the anxiety. In retrospect, it would make acceptance of your child and his problems much easier if the cold harsh truth were told. Sure, you might not accept it immediately but over a period of time it would provide a foundation for building new, more realistic dreams and hopes for your child. Too often your dreams are shattered in slow motion leaving you with nothing but despair.

It is important as a parent to have goals and aspirations for your child regardless of how simple they may be. Perhaps just feeding himself or changing clothes or speaking. It is easy to take pride in your son if he is the star quarterback, student or whatever. You know you have come to accept your handicapped child when you can genuinely take pride in the fact that he has just learned to catch a ball!

An important gift my son gave me was not pride in his accomplishments but rather a different and deeper perspective of life. It is one thing to rejoice in accomplishment. Many people do that very successfully. It is what we have all been conditioned best to do. It is quite another matter to learn how to deal with fear, self-doubt, guilt and anxiety. It becomes a true test of your inner strength and character. You really learn to know yourself and your emotional capability.

An even more important gift has been the insight, compassion, and understanding toward others developed as a result of my own experience. Colleges and universities teach courses in philosophy and psychology the finest teachers of all are our handicapped children." (Written by Ron Schneider)

*** "We started our question of "what's wrong with our child" over twenty years ago. Our pediatrician at first thought he was deaf. I dropped half of his instruments on the floor to prove there was no reaction on our son's deaf ears. We started on the rounds of big name hospitals and clinics, and big medical bills. We were told that I rejected him as a baby and also that one of us must be at the genious level. A positve point the doctor told us was that we were lucky our child looked normal. Coping with the knowledge of your child's handicap can be a blow, but coping with "this is all my fault" can knock you down for the ten count. Special education therapists feel that

parents of handicapped children pass through four stages--fear, anger, loneliness, and guilt. After a period of time I can honestly say it was arger that finally lead me to take positive action in my life. Today medicine now feels that the cause of autism is biochemical, although the prognosis is still very poor.

We now had a son who walked, fed himself, and looked normal. He spun anything that would turn a circle, never listened to us talk, screamed, laughed, or banged his head for no apparent reason. He always ran flapping his arms like a bird ready to take off, and went through at least one rocking chair a year. At the age of four, he had his first grand mal seizure, which I later found out is very common in autistic children. We looked for schooling for our son only to discover there was nothing. Twenty years ago education had no idea where to start with a child like this. As his seizures became more severe and frequent, our goal became to keep him alive through the status seizures. At the age of seven we placed him in an institution. A part of us died that day. I remember the nurse asking me if I wanted to see his bed. I ran crying to the car, feeling like this was a bad dream. Little did we know the nightmare would get worse. We started noticing in our year-and-a-half-old daughter many of the autistic characteristics that her brother had displayed. Never did I ever imagine we would be going back to the same hospitals and clinics again. The doctors, on the whole, seemed better informed, the diagnosis was quicker--your child is suffering from infantile autism.

Good news, a law had been passed which stated all handicapped children were to receive special education. At the tender age of three we sent our child to school. Two goals were set, to teach our daughter

to speak and to stop her bizarre behavior patterns. After a year of speech therapy, we discovered she had no inner language. She only seemed to recognize her name, and come and eat. She resisted all forms of learning and seemed to be sinking more and more into another world. Over the years we had acquired a great deal of knowledge about autism on a medical level, but not much on a teaching level. We decided to make up our own program. Our first objective was to get her to understand one word--COME. Why the word come? Simply because I was tired of chasing her all over hell. She never stopped running unless she hit a wall or a fence. We finally hit on the idea of cupping our hands around her ears and eyes, and pulling her along yelling "come."

She had to hear, she had to look at us saying come and whether she liked it or not she had to walk in that position. After a period of time she would come when called because if she turned and ran, she knew the horse blinders would come on again. Another problem was that she would never give any eye contact, again we used the horse blinder method, but added a reward of a peanut. The longer the eye contact the more peanuts. We had noticed for a long time she would use our hands to pick up objects, we thought this was a form of her telling us what she wanted. To my shock, one day she went up to another child's mother to go home from school. In the future, when I stood with the other mothers she rarely picked out the right mother. In all respect, I had become a robot mother. We had always given the children love, but it had been one sided, we had to teach her to love and interact. One day my husband was chewing gum, she kept trying to get the gum with her fingers. We held her hands down and told her to

kiss for some gum. Presto! That wasn't so bad. She loved to play with body lotion. We would place a spot of lotion on our arm or face, if she wanted to finger paint with lotion she had to touch us. I can now say with a great deal of joy that she shows a great deal of affection and love without any aides, in fact, she hardly lets us out of her sight.

Our greatest problem was the lack of speech. I had given up on speech therapists. After the age of seven we gave up on her speaking. Her teacher and I traveled around the state looking at sign language demonstrations versus using a signing board. Sign language was decided on. Our goal was one sign a month. Naturally we started with the sign for candy, with the reward being candy. The sign took 2½ long months to learn. Again she threw up every roadblock to learning. In her frustration she started biting her arm. Should we continue or stop? We continued on, we would tackle the self-mutilation problem later. Our big hurdle was the sign "mad." This was an abstract idea. I remember the first time she used the sign when she was actually mad. The sign is banging two closed fists together. All the anger she seemed to possess at that moment seemed to spill out of her fists.

At the age of seven we only had our daughter partially toilet trained. She would spread feces on herself, rugs, furniture, or ignored the mess in her pants. Mothers have been known to go into a frenzy over this with normal children. We finally decided she liked the smell of feces. Her hand flapping was due to her sensitivity to light, could her sense of smell be underdeveloped? We needed a strong smell that could substitute for the smell of feces. Vinegar

on a was-cloth was tried. She was overjoyed and carried the cloth with her all the time. Our house smelled like a giant salad. Every time she smeared feces, we took away the cloth. She finally made her choice, vinegar. Within three weeks we had bowel movements done in the proper place. The vinegar washcloth was gradually faded away. I sound like the merchant giving away all the tricks of the trade. A problem to me is the center of a circle. You come in from one angle, if that doesn't work you retreat, think out your next move, and move in from a different direction.

A great teaching and entertainment aid over the last ten years has been our daughter's picture boards. We take pictures of all activities she engages in. We glue them to a masonite board and laminate the board. She spends a great deal of time each day looking at the pictures of friends, events, animals, etc. The picture board stimulates her memory, and by pointing to a particular picture, we can tell a story to her.

Medically speaking, not many gains have been made over the years. Educationally, many giant steps have been made. Teachers are now trained to teach the autistic and larger school districts have special autistic classes. Soon we will have year-round programs for the autistic.

Today there is a national and state society for autistic children with emphasis on providing support for families and the encouragement of both medical and education research. The research includes: the use of mega vitamin therapy, the use of B-6 and B-15 as well as diet. Another potential causative factor currently receiving a great deal of attention is the D.P.T. vaccine. Many children who have a negative

reaction to D.P.T. exhibit the same characteristics as autistic children. In all likelihood, there is no singular cause and consequently there will be no singular cure.

Webster defines the word coping as the attempt to overcome problems and difficulties. As parents of autistic children we have many problems and difficulties, the challenge is to confront the problem. We must first, however, set aside the bitterness and guilt for all of this is time consuming and eroding. You have to learn to live one day at at time. Each day is a new beginning." (Written by Penny Schneider)

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